

**Supporting Families Through the Acute Phase of the Pediatric HSCT  
Experience**

BY

KELLY A. LANKIN

B.S., Northern Illinois University, DeKalb, Illinois, 1990

M.S., Northern Illinois University, DeKalb, Illinois, 2011

THESIS

Submitted as partial fulfillment of the requirements  
For the degree of Doctor of Philosophy in Nursing Sciences  
in the Graduate College of the  
University of Illinois at Chicago, 2020

Chicago, Illinois

Defense Committee:

Patricia Hershberger, Chair and Advisor

Cynthia LaFond, Rush University

Eileen Hacker, Indiana University

Teresa Savage

Catherine Vincent

This thesis is dedicated to all of the children and their families, who are battling life-threatening diseases requiring hematopoietic stem cell transplant treatment. May the findings of this research help to provide some comfort during this very complex and challenging experience.

## **ACKNOWLEDGMENTS**

I would like to first thank my dissertation Advisor and Chair, Patricia Hershberger, for her continued guidance and mentorship with this very important research. She was instrumental for my success by sharing her remarkable knowledge of qualitative research methods, and provided strong leadership that unified the dissertation committee. Much gratitude is extended to Cynthia LaFond for her support in helping me to learn the process of gaining IRB approval. I am sincerely grateful for all of the stem cell transplant expertise that Eileen Hacker brought to this research, and to Teresa Savage for her knowledge with qualitative methods and palliative care. Finally, I would like to thank Catherine Vincent for her overall wealth of knowledge that contributed to this dissertation and to my overall success.

I would also like to acknowledge all of my professors for your diverse insight and my PhD student colleagues for experiencing this journey with me. I am grateful to The DAISY Foundation and the Society of Pediatric Nurses for their support of this research. I would also like to thank James LaBelle, MD, PhD, Associate Professor of Pediatrics, and Director of the Pediatric HSCT program at the University of Chicago Medicine, Comer Children's Hospital for his contributions to the study. The Nurse Advisory Committee deserves recognition for their contributions that ensured this research has a clear path towards improving the care of the pediatric stem cell transplant families.

Most importantly, I would like to thank my family, friends, and coworkers for your endless support and encouragement. I especially want to thank my dad, who as a research scholar, is so thrilled that I was able to complete this very important research.

KAL

## TABLE OF CONTENTS

<u>CHAPTER</u>		<u>PAGE</u>
I.	SUPPORTING FAMILIES THROUGH THE ACUTE PHASE OF THE PEDIATRIC HEMATOPOIETIC STEM CELL TRANSPLANT (HSCT) EXPERIENCE: PERSPECTIVES FROM PARENTS AND NURSES	
	A. Background .....	1
	B. Methods .....	4
	a. Design .....	4
	b. Sample .....	4
	c. Recruitment .....	5
	d. Measures .....	5
	e. Procedures .....	6
	f. Data Analysis .....	6
	C. Results .....	7
	a. Community Support .....	8
	b. Social Support .....	12
	c. Family Support .....	17
	d. Healthcare Team Support .....	19
	D. Discussion .....	25
	E. Limitations .....	28
	F. Practice implications .....	29
	G. Conclusion .....	30
II.	PARENTAL STRESSORS, COPING, AND ADAPTATION RELATED TO THE PEDIATRIC HEMATOPOIETIC STEM CELL TRANSPLANT EXPERIENCE: PERSPECTIVES FROM PARENTS AND NURSES	
	A. Background .....	51
	B. Methods .....	54
	a. Design .....	54
	b. Sample .....	55
	c. Measures .....	55
	d. Procedures .....	55
	e. Data Analysis .....	56
	f. Conceptual Framework .....	57
	C. Results .....	57
	a. Stressors .....	58
	b. Coping .....	64
	c. Adaptation .....	68
	D. Discussion .....	72
	E. Strengths and Limitation .....	76
	F. Practice Implications .....	77
	G. Conclusion .....	78

<u>CHAPTER</u>	<b>TABLE OF CONTENTS (Continued)</b>	<u>PAGE</u>
H.	Appendices	
	a. Institutional Review Board (IRB) Approval .....	101
	b. Clinical Trials Review Committee (CTRC) Approval ...	103
	c. Nursing Research Committee Approval: University of Chicago Medicine (UCM) .....	104
	d. Clinical Care Center Review Form .....	105
	e. IRB Authorization Agreement .....	106
I.	VITA .....	108

## LIST OF TABLES

<u>TABLE</u>	<u>PAGE</u>
I. FAMILY SUPPORT INCLUSION AND EXCLUSION CRITERIA:	
PARENT AND NURSE .....	42
II. FAMILY SUPPORT INTERVIEW GUIDE:	
EXAMPLE QUESTIONS .....	43
III. FAMILY SUPPORT: PARENT DEMOGRAPHIC DATA .....	44
IV. FAMILY SUPPORT: NURSE DEMOGRAPHIC DATA .....	45
V. SAMPLE QUOTATIONS: FAMILY SUPPORT .....	46
VI. STRESSORS, COPING, AND ADAPTATION INCLUSION CRITERIA:	
PARENT AND NURSE .....	92
VII. STRESSORS, COPING, AND ADAPTATION INTERVIEW GUIDE:	
EXAMPLE QUESTIONS .....	93
VIII. STRESSORS, COPING, AND ADAPTATION:	
PARENT DEMOGRAPHIC DATA .....	94
IX. STRESSORS, COPING, AND ADAPTATION:	
NURSE DEMOTRAPHC DATA .....	95
X. SAMPLE QUOTATIONS: STRESSORS, COPING, AND	
ADAPTATION .....	96

## LIST OF FIGURES

<u>FIGURE</u>		<u>PAGE</u>
1.	Pediatric HSCT Family Support Model .....	50
2.	Family Support, Coping, and Adaptation Conceptual Model of Resilience: Pediatric HSCT .....	100

## **LIST OF ABBREVIATIONS**

BSN	Bachelor of Science in Nursing
GVHD	Graft Versus Host Disease
HSCT	Hematopoietic Stem Cell Transplant
IRB	Institutional Review Board
MSN	Master of Science in Nursing
PICU	Pediatric Intensive Care Unit
PTSD	Post Traumatic Stress Disorder
MD	Medical Doctor
NP	Nurse Practitioner
RMH	Ronald McDonald House



## SUMMARY

Hematopoietic stem cell transplantation (HSCT) has become a widely accepted method for treating various pediatric malignant and non-malignant conditions, but does come with many challenges including 35% mortality rate at one year, morbidity brought on by acute and chronic complications, and significant psychological challenges of both the child and the family. The aims of this descriptive qualitative study incorporated the views of parents and nurses, and include: 1) to describe how families are supported through the acute phase of HSCT, when the child is hospitalized (first manuscript) and 2) to describe the challenges that parents face during their child's HSCT hospitalization and how parents cope and adapt to this experience (second manuscript).

Using a stratified purposeful sampling method and eligibility criteria, ten parents and fifteen nurses were recruited from an academic medical center in the Midwest to participate in a demographic survey and semi-structured interviews. The Resiliency Model of Family Stress, Adjustment, and Adaptation guided the design, interview guides, directed content analysis, and summation.

Support groups and/or support from individuals going through the same experience were most beneficial to families, and family presence during the hospitalization was crucial. Family obligations, transplant-related complications, and a breakdown in communication with the transplant team were described as the most challenging parental stressors to manage, with hopefulness for a cure seen as a positive coping mechanism. As families are forced to adapt to new routines, healthcare professionals must assess the ability of families to manage the stressful challenges of pediatric HSCT and intervene when families are lacking in support structures.

# **I. SUPPORTING FAMILIES THROUGH THE ACUTE PHASE OF THE PEDIATRIC HEMATOPOIETIC STEM CELL TRANSPLANT EXPERIENCE: PERSPECTIVES FROM PARENTS AND NURSES**

Approximately 3,500 children require a life-saving allogeneic or autologous hematopoietic stem cell transplant (HSCT) each year in the U.S for malignancies, anemic conditions, immunologic and metabolic conditions, or solid tumors (National Cancer Institute, 2017). Although allogeneic HSCT (donated cells) is associated with higher rates of complications and mortality, autologous HSCT is not without its challenges (Kolins, Zbylut, McCollom, & Aquino, 2011). Several investigators report overall mortality rates of pediatric HSCT to be around 35% at one year and mortality rates from 42% to 76% in children who have experienced acute complications, including respiratory failure, renal failure, liver disease, and sepsis, within the first 100 days after transplant (Rowan et al., 2016; Zinter, Dvorak, Spicer, Cowan, and Sapru, 2015). With the threat of fatal complications, uncertainty of prognosis, and a prolonged hospitalization for the HSCT experience, many children and families face significant psychological effects during the acute phase of the transplant process.

## **Background**

It is well known that children exhibit significant physical and psychological effects after pediatric HSCT, which affect family functioning, and range from medical complications to social isolation (Lahaye, Aujoulat, Vermeylen, & Brichard, 2017; Ishida, et al., 2010; Tanzi, 2011; Ingreski, Shaw, Gray, & Janicke, 2010). Psychological effects of the parents and siblings have also been identified in numerous studies. Approximately 50% of parents report Post Traumatic Stress Disorder (PTSD) symptoms that occur within the first three months after the child's HSCT, and at least 15% of the caregivers demonstrate high levels of distress, including anxiety,

depression, burnout symptoms, and PTSD at five years post transplant (Virtue et al., 2014a; Virtue et al., 2014b; Riva et al., 2014). Strong evidence has been linked to a decrease in emotional functioning of parents whose child underwent HSCT and experienced clinical complications of the transplant, including acute graft versus host disease (GVHD), organ toxicity, and early-onset infection (Terrin, Rodday, Tighiouart, Chang, and Parsons, 2013). Parents and siblings often serve as the children's HSCT donors. As children suffer complications or death after HSCT, this can cause feelings of anxiety and guilt among the donor, adding to the psychological distress of the HSCT process (van Walraven et al., 2012; Wilkins and Woodgate, 2007a, 2007b; MacLeod, Whitsett, Mash, & Pelletier, 2003). Non-donor siblings also have their own challenges with pediatric HSCT, including social isolation, exclusion from the family, anxiety, depression, unmet needs, and an overall feeling of an interruption in family life (White et al., 2017; Erden, Kuskonmaz, Cetinkaya, Unal, & Ozsungur, 2019; Packman, Gong, VanZutphen, Shaffer, & Crittenden, 2004; Pentz et al., 2014). There are many complexities surrounding pediatric stem cell transplantation and HSCT success is reliant on a continuum of care both within the health care system and within the family structure to address uncertainties in outcomes and quality of life (Terrin et al., 2013; Pennarola et al., 2012; Norberg et al., 2014; Santacroce, 2003).

Family support during acute pediatric illness remains vital to maintain the family unit as functional and address all of the described psychological effects that arise from pediatric HSCT. Care models that incorporate a shared care approach and continuity of care are key to provide positive outcomes, reduce parental anxiety, increase parental satisfaction, and improve communication between members of the health care team (Curtis, Foster, Mitchell, & Van, 2016). The recovery process after HSCT is described as a family experience involving the

challenges of caring for the transplant recipient, caring for other children in the household, and maintaining some kind of normalcy in the daily routines (Young, 2013).

Some investigators have reported strategies that help families through the HSCT experience. Parental activation, the process of becoming informed to make decisions, helps parents communicate and collaborate with the health care team, and care for their children (Mayer et al., 2010; Mayer et al., 2009). The Internet, health care team, and printed materials were most accessed by families to gain knowledge about their child's transplant, while health care professionals, family and friends, educational classes on HSCT, and support networks were accessed as support systems throughout the first year after transplant (Mayer et al., 2009). Families have also identified that their personal needs and the family's emotional needs were not met during the first year of the transplant experience (Mayer et al., 2009). There is some interventional research addressing the psychological effects of the child and parents, including a parent-focused social-cognitive processing intervention for caregivers, a massage intervention for the parent and child, and a music intervention for the child (Manne, Mee, Bartell, Sands, & Kashy, 2016; Lindwall et al., 2014; Burns, Robb, Phillips-Salimi, & Hoarse, 2010). The palliative care team is a model that treats the whole family and not just the child, and can play a role in the psychological support of the family members through the facilitation of communication with health care professionals, continuity of care, parental involvement with decision making, and symptom management for the child (van der Geest et al., 2014). Although some interventions were found to be statistically significant to reduce psychological effects, others were not significant, suggesting that parents suffer extreme anxiety during the acute phase of the transplant regardless of interventions. There is a significant gap in the literature that outlines interventions for families during the acute HSCT experience.

In summary, pediatric stem cell transplantation comes with significant physical risks to the child, as well as significant psychological risks to the entire family. Because it has been reported that up to 50% of parents suffer from PTSD during the acute phases of the child's transplant, it is vital that the health care team not only prioritize treating and curing the child, but also supporting the family. With prolonged hospitalizations during the acute phase of the HSCT, these families experience many immediate challenges that need to be addressed.

### **Purpose**

The aim of this study was to provide an understanding of how families are supported through the acute phase of HSCT, while the child is hospitalized, from the perspectives of the child's parents and the nurses caring for these children. Support from the community, social resources, family, and healthcare professionals, was the center of the focus, as guided by the conceptual model. Participants were asked about support interventions that were either beneficial or absent, which will help guide further research.

### **Methods**

#### **Design**

A qualitative descriptive design was chosen for this study. (Kim, Sefcik, & Bradway, 2017; Sandelowski, 1993; Sandelowski, 2000). An adapted model from *The Resiliency Model of Family Stress, Adjustment, and Adaptation* (Hill, 1949; McCubbin, Gauble, & Patterson, 1982; McCubbin & McCubbin, 1993; McCubbin et al., 1996; Weber, 2011) guided the design, interview guide, analysis, and summation of this study.

#### **Sample**

Data were collected at an academic urban children's hospital in the Midwest, using a stratified purposeful sampling method (Patton, 2015) and eligibility criteria were met (Table 1).

Data saturation was reached at 12 nurses and 8 parents (O'Reilly & Parker, 2012; Ulin et al., 2005). Parents were defined as the biological parent, or more broadly as the designated caregiver (e.g., family member such as grandparent, aunt; legal guardians) who is actively involved with the care of the child in the hospital unit (Knafl & Van Riper, 2017).

## **Recruitment**

Nurses were recruited passively through flyers containing study and contact information for the research team and through unit staff meetings. The pediatric HSCT Nurse Practitioner (NP) team recruited the participants during an outpatient clinic visit or on the inpatient unit when the child was admitted for their HSCT, using a script and brochure with study information. The interviewer then contacted parents after the child's admission for consent and the interviews. Recruitment occurred from August 2019 to August 2020 and included two stoppages due (1) workforce disruption and (2) COVID19 pandemic.

## **Measures**

All participants completed a demographic survey and participated in a semi-structured interview (Table 2). The semi-structured interview questions were based on the conceptual framework and incorporated the following concepts: community resources, social resources, family support, and healthcare team support (Kallio, Pietila, Johnson, & Kangasniemi, 2016). The parents provided an interview within one week from discharge while the child was still hospitalized. An optional follow-up interview for the parent group was offered at least 24 hours after the initial interview (Dempsey, Dowling, Larkin, & Murphy, 2016). If two parents were recruited from one family, the parents were interviewed separately, which allowed the research team to identify differences between family members who have different roles (Kronenberger et al., 1998; Barrera, Atenafu, Doyle, Berlin-Romalis, & Hancock, 2012; Parsons et al., 2006). The

nurse perspectives were focused on the general pediatric HSCT population and not specifically on the care of a particular child. Therefore, they were not paired with the parents.

## **Procedures**

Approval from the Institutional Review Board (IRB: 19-0308) at the data collection site prior to initiating data collection was obtained. All qualitative interviews were consented by the participant, held privately, face-to-face, and at the convenience of the participant, then audio-recorded, transcribed verbatim, and checked for accuracy after transcription. Field notes taken during the interviews and the transcribed interviews were used for data analysis (Seidman, 2013; Ulin et al., 2005). A small token was provided to all participants for participation in the interviews as described in the grant proposals (\$30.00 gift card for the first interview; \$15.00 for the second interview). A Nurse Advisory Committee (not study participants) from the pediatric HSCT unit was formed to work closely with the investigators and provided input into the interview guides, reviewed themes, and helped guide a dissemination plan. Careful attention was paid to maintaining confidentiality and a safety-monitoring plan was in place to address psychological distress (Koenig, Back, & Crawley, 2003; Kaiser, 2009).

## **Analysis**

The data analysis for the aim in this study followed a directed content analysis approach, assisting in the validation of the conceptual framework (Hsieh & Shannon, 2005). The four main themes guided the analytic process: community support, social support, family support, and healthcare team support. Interview passages from parents and nurses were categorized into the predetermined codes, patterns, and themes using an inductive approach. The matrix method helped to reduce and display the data, and devise conclusions (Miles & Huberman, 1994), and NVivo 12 for Mac was used to organize and store the data from the interviews and assist in

organizing the codes and patterns into themes as they emerge (Peacock & Paul-Ward, 2006). A team approach for the analytic process was used to maintain dependability and codes were monitored to keep them well defined (MacQueen, McLellan-Lemal, Bartholow, & Milstein, 2008). Two nurses were brought back to review the transcripts and the meaning of the interviews (Creswell & Miller, 2000). Triangulation was used to search for convergence among the different data sources, including parents and nurses (Ortlipp, 2008; McCabe & Holmes, 2009; Mays & Pope, 2000).

## **Results**

Ten parents from six families and fifteen nurses from the pediatric oncology/HSCT inpatient care unit completed a demographic survey and one semi-structured interview, each within a twelve-month time frame (Table 3 & Table 4). Two parents completed an optional second interview with the other eight parent participants either declining the second interview or their child was discharged within 24 hours of the first interview. The parent interviews lasted between 20(min):39(sec) to 56:08 (mean 37:28) for the first interview, and 3:07 to 7:17 (mean 5:15) for the second interview; the nurse interviews lasted between 13:08 to 51:37 (mean 26:29). Fifty percent of families had a child who underwent an autologous HSCT and 50% were allogeneic for diverse underlying diseases.

The directed content analysis of the data used the main themes from the Family Support Conceptual Model, and adaptation from the Resiliency Model of Family Stress, Adjustment, and Adaptation (Figure 1). Subthemes emerged within each main theme that outline the parents' most beneficial support during the child's hospitalization for HSCT. Below, each of the main themes is delineated with appropriate subthemes (Table 5).



## **Community Support**

Community resources were defined as those found through church/religion/ spirituality, disease specific foundations, employer, school districts for both the hospitalized child and the siblings, and random acts of kindness from people within the surrounding community. As the parent group has more perspective about support they receive outside of the hospital setting, parent participants shared more robust experiences in this category than the nurse group.

### ***Church/Religion/Spirituality***

Many of the parents described the roles that religion and spirituality play in helping to support families through their child's illness and hospitalization. Some church experiences were described as randomly donating to families in need while others take a more active role with supporting the family as stated by one father:

*In fact, a lot of the friends who've played nanny for us are, friends we know through church . . . one of our members is a really good friend, and her daughter had retinoblastoma . . . she's been through this, so she's been a big support. And she'll come and get our five-year-old daughter and give her some one on one time* (Father 4)

Another parent discussed that she is not involved with a church or religion, but is more spiritual in her approach to coping with her daughter's illness. *"I'm not religious, but I am spiritual. And I do believe that the universe will treat you as you treat the universe. And I mean by that is if you keep putting positivity out, you'll get positivity back in"* (Mother 1).

Nurses agreed with the parents in describing the role that church/religion/spirituality play in supporting families through the HSCT experience but that there may be obstacles during the child's hospitalization. One nurse commented that visitor restrictions, which are in place to protect the immunocompromised child, often inhibit support from religious groups or

individuals. “. . . *If they’re part of a faith community of any kind, they will draw on that. But because of the visitor restrictions, oftentimes, their person can’t come, and they (parents) don’t want to leave the bedside*” (Nurse 8).

### ***Foundations***

Support from community organizations and disease specific foundations were a common theme among parents. These foundations supported families emotionally, educationally, and financially, and the family either accessed them or the foundations randomly reached out. One parent shared the emotional support that he received from a local foundation.

*We’re not the type to go reaching out for help. We’re usually the type who are helping, right? And so we got lucky. There’s this organization called Cal’s Angels . . . The executive director lives in our town . . . Two hours later, they (exec. Director and daughter who had cancer) were sitting in my house . . . It’s what we needed. His words to me were “I can tell you are like me. You’re a type A. You want to fix it” And he said, “The faster that you learn that you can’t fix this, the better off you’re going to be . . . And the second thing, you need to learn how to say yes to people who want to help you*  
(Father 3)

### ***Community Support***

Several parents described community support as more generalized and that many individuals in the community reached out to help as random acts of kindness. Parents that described generalized community support relayed this as overwhelming and emotional, and are incredibly grateful for how compassionate, caring, and sympathetic random people in the community were to their families.

*We kind of are in a state lately where it’s just . . . this world’s kind of creepy, and*

*everybody's so self-absorbed with stuff. But when it came down to it, it was like, Wow.*

*There really are a lot of good people in this world" (Mother 5)*

### **Work Support**

Although nurses described challenges with families having to balance work and finances with their child's illness and hospitalization, the parents shared that they were greatly supported by their employers. Several parents expressed their experiences of being allowed to work at home, even if the employers do not allow that work strategy. Employers were described as very empathetic, caring, and willing to work with the parents to help support a continued income and often times insurance coverage.

*My job is working with me . . . when I handed over my resignation, they wouldn't accept it. They told me, "No. We're going to work with you with this because it's something that's unforeseen and you can't control this. Your daughter is sick." Because I haven't even been there six months yet – my sixth month is next month. So most jobs, they'll be like, "Okay. Well, bye." But they didn't (Mother 1)*

The nurses acknowledged the stress of having to work during the HSCT experience, but did agree with the parents that most employers are accommodating. One nurse describes challenges with the Family Medical Leave Act in that there are limitations to taking an extended leave of absence from a job.

*The majority of the families that I have interacted with, their employers have been as understanding as they possibly can be. But, unfortunately, in the American system, a lot of these companies' hands are tied. They don't have an internal policy about parents taking extended leave to care for a sick child beyond the federally mandated FMLA. But I do feel like most of the companies that these families work for have done what they can*

*to try and be accommodating. I have not had a lot of families that have complained about their job (Nurse 8)*

### ***School Support***

The local school systems were illustrated as a strong support for most of the parents, siblings and the family as a whole. Siblings face challenges with pediatric HSCT including the donation process, missed school, and disrupted family dynamics and routines. Any support from the school was described as essential. The sick child keeping up and not falling behind was a theme that was important to a lot of families. Parents discussed the use of tutors, support from their teachers, and a concerted effort to help these children stay on track with their schoolwork.

*He had all honors classes and one AP class, so he was a little nervous about being behind . . . And the school's been wonderful as far as accommodating him, and they didn't make him do some of the busy work that wasn't essential. He took all the tests and did everything he needed to and finished the first semester a week early (Mother 3)*

One family shared the experience that their son played trumpet in the school band, and he did not miss one concert during his cancer treatment. Both parents became tearful in describing the emotional support that was offered to their son.

*So it was the last high school band concert . . . and we see the kids filing in . . . and they're all wearing purple ribbons. That was when I knew that this was bigger than just my son. There's good in here someplace. I just can't see it. That's when I saw it. That's when I saw it (Father 3)*

Fundraiser support was also a theme in describing the assistance from the schools that both the child and siblings attend. *"And our daughter's school, it happens to be a Catholic school – they do a St. Baldrick's event every year. Last year and this year, they're kind of*

*honoring him on their St. Baldrick's day shirts, very supportive"* (Mother 6). Just one nurse talked about school fundraisers. *"And the schools for the kids do a lot of fundraisers and benefits and T-shirt sales and things like that to help"* (Nurse 10).

Teenagers diagnosed with cancer while in high school have different challenges when they continue their treatment into their college years. A mother described that her son doesn't have the previous high school activities and friends who were there for support, but that her son's teachers continue to reach out.

*Now, because his whole senior year of high school, he was diagnosed. So his high school community was great. It was almost like I kind of felt for him like he was kind of going to be in this void area where he doesn't have the high school stuff to fall back on.*

*95% of his friends are away at school, and now he's home kind of doing this again. His high school teachers still email and text and call* (Mother 6)

## **Social Support**

Social support encompassed social media and online groups, support groups and individuals, Ronald McDonald House (RMH), and friends. Both the parents and the nurses shared that socialization and support from other families experiencing the same or similar situations was most helpful for families, either through online communication or face-to-face contact.

## ***Support Group***

Support groups were described by most of the parents and the nurses as being the main avenue that the parents turn to for information and encouragement. Five nurses described a neuroblastoma website that connects families socially, in which they can share their experiences, treatment plans, and overall journey.

*A lot of families find support from online groups. So they will often join neuroblastoma groups on Facebook, and then they can kind of walk that journey with other people who are also doing that same thing. And a mom can be a friend with another mom out in Washington who's also getting this treatment. Or this mom heard about a therapy in New York, and now our mom is asking us about it (Nurse 10)*

Although beneficial for emotional support, some of the nurses shared that online groups are not always appropriate for receiving medical advice. Families sometimes obtain medical advice from online sites that may not be appropriate. One nurse shared:

*So, it may not be the most beneficial because I feel like that's the way a lot of misinformation gets spread. Or if someone posts something that says, 'Oh, my kid's getting these therapies' and then someone else posts, 'oh, our doctor said that was the worse thing you could do' – it's kind of a double-edged sword. So it's good for support. It's not good for medical support (Nurse 10)*

Parents described that they have turned to online support groups as well but several shared that there are some challenges, which mirrored the concerns as stated by the nurses. Emotional support was beneficial, but these support websites did not always offer sound medical advice, causing some parents to second-guess their decisions. Online connections are not always hopeful. Unfortunately, not all of the children whose parents connect have positive outcomes, which can be less encouraging.

*I have that Fanconi anemia support group that, because it's such a rare disease, it's all people that either they have it or their kids have it. And it's nice to get tidbits, but sometimes, when you're on there, it feels very culty. It's like if you're not going to Cincinnati or Minnesota, or I think, New York is another one of the FA centers, they're*

*always like, 'Oh, you need to go to a FA center'. And so then forever, I was freaked about, 'Am I going to the right hospital? Am I just coming here because it's close and I'm being lazy?' . . . All the doctors assured me that just because we're not a FA center, we follow all the same protocols and doctors talk – And they were really comforting in that aspect (Mother 5)*

Online support groups are widespread, but one family described that one-on-one (in-person) support with another family whose teen battled the same cancer was more beneficial than meeting as a group. This family met with the recovered teenager and his parents, which was a support for the whole family. The parents became friends and one father describes the great emotional support they received as they embarked on some setbacks.

*So when this all came down, we asked if there was any way they would be willing to talk to us to kind of let us know, from their perspective, what to expect and what they went through. And they were more than happy to do that. So that really helps, talking to his mom. And our son actually texted with Brandon, and I think that really helped him. And I know once he was admitted to the hospital, he started texting him on his own again. And I could see he was a lot more relieved, just a little less nervous about things after talking to Brandon” (Father 3)*

The most prominent theme that emerged when nurses and parents were asked about support interventions during the hospitalized time frame was to offer support that connects families going through the cancer and HSCT experience. One mother had a daughter who experienced several complications that were almost life ending, and this child had a prolonged PICU stay. *“I think I need that. I need a support group, somebody that's actually going through what I'm going through right now and also one that survived this because I need to know”*

(Mother 1). Only one parent described needing more self-care resources for parents, but this same parent found the emotional support most beneficial. Several of the nurses also described the need for a more structured support group on the in-patient pediatric HSCT unit that would help connect families going through similar experiences, such as a weekly coffee hour or meeting.

*We have a monthly dinner, and families love that. It's so good for them to all eat together, and say, 'Come outside these wall and see other families . . . you're behind that door. I'm behind this door'. And I think maybe a weekly kind of parent group meeting . . . there's other families that are going through the same thing you're going through. Do you want to come out of the room for an hour on a Wednesday and talk to this mom down in this room? (Nurse 10)*

### **Social Media**

Facebook was described as a means to post the child and family's journey with the HSCT experience. Many families struggle with constant friends and family reaching out for updates and requests of how they can help. Social media outlets allow families to post updates about their sick child, which takes the burden off of having to communicate individually with large amounts of family and friends, who all want updates.

*There's plenty of drama and negative things on social media, but for this, Facebook's been a great thing. The first week we were in the hospital, I was getting 40 or 50 calls a day from people who wanted to know what they can do and what's going on. I kind of finally decided I just need to start posting a daily update so everyone who wants to read can read it on Facebook and if they want to see what's going on they can and it's just easier rather than telling the same thing 50 times (Father 4)*



Not all parents chose social media as a means for communication. One mother described her aversion to Facebook and that posting is more of a burden to engage socially, which she was trying to avoid. Communication through social media was described as a personal choice and a tool that some families accessed for support.

Several nurses agreed that Facebook was the most common social media outlet for parents and that it gives the parents something to do while they are sitting in their hospital room with their sick child. *“Social media, posting on Instagram, Facebook, getting support through there – I see a lot”* (Nurse 4).

### ***Friends***

Although not a strong theme, two parents talked about support from friends that helped both financially and emotionally. Friends are available for emotional support but are not often available to physically help the parents. A mother shared that she has a friend to talk to, but that this friend does not physically help her out, which is the support that this mother needed most. A second parent shared that her best childhood friends helped to raise money for the family. *“My two best friends, they’re like my sisters. I’ve known them since I was like eight. They threw a fundraiser for us at a Brewfest, and we got money from that”* (Mother 5).

### ***Ronald McDonald House (RMH)***

The parents did not talk about RMH as a support structure (none of the parents interviewed were staying at RMH) but the nurse participants shared their perspectives of the support that RMH provides the families. RMH provides a home away from home, including meals, socialization with other families, and community support, so that families can stay together when a child is hospitalized. Families often connect through their stay at RMH.

*RMH is, I feel like, a huge support group for them. We had a patient whose mom really*

*grew close to one of the other parents in the RMH and kind of used them as a confidant and someone she could relate to, because I feel like their experience is very unique and It's hard for their friends or, perhaps, parents to understand what they're going through.*

(Nurse 4)

## **Family Support**

Family support consists of those individuals that the hospitalized family draws upon from their own family/kin. The subthemes that emerged as family support individuals include grandparents and other extended family. One parent described a lack of family support, which is discussed.

### ***Grandparents***

Nine out of ten parents shared that the grandparents are the most present and helpful family member during the child's illness and hospitalization for HSCT. The grandparents were described most with helping to watch the other children. The importance of taking breaks was shared as crucial and that the grandparents played a large role in helping parents to get away, even if just for a short time. One parent shared the convenience of having grandparents who live close.

*My wife's parents, they live close by, and they're always around, helping with my daughter . . . she's at school most of the day. And if we're not around, she can go right over to my wife's parents who live right across the street from the school (Father 6)*

Nurses agreed with the parents that the grandparents were the most present, and added that visiting restrictions deterred most others besides the grandparents from visiting.

*"Grandparents relieve the parents so that the parents can see the other kids to just take a break"*  
(Nurse 12). Isolation guidelines are described as strict during the transplant hospitalization to

protect the immunocompromised child. *“Unfortunately, you don’t get to have many visitors when you are here for transplant. Usually, it’s mom, dad, and maybe a grandparent”* (Nurse 8).

### ***Extended Family***

None of the parents talked about other extended family as being a strong support during the HSCT experience, but the nurses shared their experiences with the children’s aunts and uncles and with extended family. Extended family members were described as providing emotional support and helping with other family obligations. One nurse shared her experience about an uncle that was emotionally supportive to the hospitalized child.

*I’ve had a lot of aunts and uncles that are really helpful. Specifically, there was one family, in particular, there was an uncle that was over the moon for this kid. And he would just rave about his uncle. And every time they would FaceTime and every time he would come in, he was over the moon. He was like a totally different kid* (Nurse 10)

### ***Lack of Support***

A major challenge for one family was not having any support helping with the hospitalized child. This mom described having to work full time and can’t always be at the hospital with her daughter, who had a very complicated course with a PICU admission and prolonged hospitalization.

*I don’t have any other support system like that. I’ve always been a go-getter. I always make sure that everything came together because even before I met my wife, I was a single parent. So I took care of those kids by myself. The dads didn’t do nothing. So it’s like I’ve always been the one to figure out how to fix any situation . . . So who is my support system? I don’t really have one . . . It’s just me* (Mother 1)

When parents lack family support, they can't always be present for the hospitalized child. The nurses shared their own challenges when caring for children during the HSCT experience without a family presence. The nurses described overall, they realize that families have other obligations and can't always be present with the child, especially with a prolonged hospitalization. They also shared the stressors of feeling guilty that they could not always be present for children who lacked a parental presence and having to balance other patients' needs. One nurse talked about the needs of younger children requiring more attention and the challenges of not always having a presence in the child's room.

*I think my biggest stressor is I can't be there the whole time. Especially if they don't have a family member, I think that's what's hard. And it happens often. I can't be there every second for this one patient. Even though I'm in there so much giving meds, blood, whatever they might need, I might not be able to hang out . . . And, sometimes the kids are like three years old or two years old. They get so bored. They need constant attention (Nurse 15)*

## **Healthcare Team Support**

Support from the healthcare team is an essential role during the HSCT experience. The subthemes specific to healthcare individuals emerged as most important in supporting families included: nurses, nurse practitioners, physicians, social workers, and child life specialists.

### ***Nurse Support***

The support that the in-patient nurses provide the families during the child's hospitalization for transplant was the strongest theme to emerge from the parent interviews. Nine parents commented on the strength of the nursing staff and their dedication to caring for

their children. Nurses were described as going above and beyond their call to help the families in that they are always thinking about their children.

*And I don't know how you guys do it day in and day out. I really don't. And I'm in awe of that . . . Every nurse that comes in, if not cheery, is at least never negative . . . It's like how the hell do you come to work every day on this floor? . . . You want to be here, so that's pretty special and not lost on us either* (Father 3)

Another parent reiterated how nurses exceed and go above the work they do during their shift.

*"We've had nurses who aren't caring for him that day, but they'll come in just see how things are going . . . It makes you feel like people are thinking about you beyond their shift"* (Mother 6).

With families isolated in a hospital room because of the child's immunocompromised status, several of the parents shared their need for socialization.

*There's a few of them that you can just tell that it's like they're just genuinely concerned, and they check on you when you're walking in the hallway. Or just it's nice to have a conversation with someone that's just a normal conversation. Someone I can say, 'Well, stand in here a few extra minutes and talk to me just about things' . . . It's just that I haven't talked to anyone but him (child) every day* (Mother 5)

The nurses shared at length how they support the families during the hospitalization for HSCT, and described their care in terms of building relationships, maintaining communication, advocating for the child and family, and helping the parents with respite care. Respite care remains a crucial resource for the family during a prolonged hospitalization, and nurses often sit with the child so the parent can take breaks. One nurse describes helping parents to feel somewhat normalized while they are in the hospital with adult conversation, which is also described by the parents.

*If I really have the extra time, I just try to interact with the child. Or if the child's too young or not too well, I just talk with the family because I know a lot of the parents have been here for a while. They almost need an adult conversation because they've been sitting, watching four walls, watching kids' shows. So even a little adult time, they really appreciate"* (Nurse 5)

Being proactive and meeting the family's needs is an essential role of the nurse. Nurses are positioned to connect the family with all members of the healthcare team and advocate for the child and family. *"Mainly, I just try to be their advocate . . . Whatever they are asking for, I try to make sure their questions are answered, try to find resources . . . Just meeting their needs the best I can* (Nurse 2).

### ***Nurse Practitioner (NP) Support***

The parent participants spoke highly of the nurse practitioner group from the outpatient oncology team and the outpatient stem cell transplant team. The NP's were described as "guardian angels" and that they provided holistic care to the family. However, this was not a theme that the nurses talked about in the interviews. Half way through this study, an inpatient transplant NP was added to the healthcare team. This allowed for another perspective from parents who shared that this NP role really helped bridge communication between the family and the transplant team, which was missing during the first few interviews. Follow-up with answers to questions and concerns was shared as an important role of the inpatient NP. *"She's so knowledgeable. And she'll always come here so you feel like you're kind of getting two times with the doctors . . . I'll talk to her first, and then the doctors will come back with her . . . she finds out for you"* (Mother 5).

The children are all followed by a primary team that manages their underlying diagnosis. For the transplant experience, the children are transitioned to the transplant team temporarily before transitioning back to their primary providers. Although one father spoke highly of the NPs, he shared some challenges with that transition process and had a negative experience with the outpatient NP team. This father was stressed that no one from the transplant team had met with the family, yet they wanted to schedule a procedure. Transitioning from a familiar and supportive healthcare team to another that is unfamiliar during a time of uncertainty causes significant anxiety on the family.

*You're not scheduling us to do a bunch of stuff that we are not ready to do. We haven't even met with you people yet, and you want to do all this stuff. That's not fair to us . . .*

*We've not met with your team yet . . . So I think that the communication upfront was a little regrettable. I think that certainly needs to be handled in a more thoughtful manner"*

(Father 3)

### ***Physician Support***

Parents shared their experience with the oncology/hematology team that manages the underlying diagnosis as still being present after the shift to the HSCT healthcare team. With the transition, families feel a level of comfort and continuity with a team of physicians who are familiar with their child's course, given the time of uncertainty. *"And even our oncology team, they've been up probably once a week to check on him and us. So you feel that connection to them too"* (Mother 6). The parents did share a newfound respect for the stem cell physician and his knowledge, and spoke positively about his presence in their child's care. Parents felt comforted that their child was receiving the best medical care. Because most of the physician

support with the families occurred outside of the nurse presence (emails, phone calls, texts), the nurses did not comment on physician support as something they have experienced.

### ***Child Life Specialist Support***

The strongest theme of family support that came from the nurse perspectives was support from the Child Life Specialist. The Child Life Specialist helps to provide respite care for the family and fosters a sense of normalcy. They address developmental milestones of the child and physical and emotional needs of the family. Volunteers are employed by the Child Life Department and are used frequently to help with distraction of the children and maintaining a safe environment. Most of the nurses who worked nightshift commented about the lack of support during the nighttime hours; they view the Child Life Specialists as a vital support during the HSCT experience, which could be enhanced with more shift coverage. One nurse talked about how the Child Life Specialist helps the parents with respite care.

*And it's really good when Child Life comes in and says, 'Hey, Mom and Dad, why don't you step out? Go and have coffee. We're going to play for a little bit.' Then you can see that weight kind of lift off when they come back. They're totally different people when they come back into the room (Nurse 10)*

Compliance with medical care is imperative for the HSCT to be successful. Pediatric patients struggle frequently with taking medications, and the Child Life Specialist can help with compliance challenges, and normalization during the hospitalization for the child and family.

*Child Life does do their thing and they are part of the whole process. And I know they make it a big deal on transplant day and when it's almost time to go. And sometimes, they'll make countdown calendars and try to help. There are times where they get involved or they'll do a reward thing if we're having issues with somebody taking*



*medication, or a reward to try to get the patient to be more cooperative. I feel like Child Life is a huge part of it all too (Nurse 7)*

The parents did not talk much about the Child Life Specialists as a main support system, but two did mention their role as being supportive for helping to distract the child. *“Child Life came with the video game, tablet, and headset – all the toys in the room came from the hospital – they brought all of that” (Father 2).*

### ***Social Worker Support***

The Social Worker team provided family support both emotionally and financially. Financial assistance was described as helping to pay bills, providing meal vouchers, and offering travel vouchers. They also help with insurance challenges and provide emotional support to the family. Nurses shared that Social Workers are a resource to the nursing staff in helping them to navigate questions for the family. One parent shared how the financial assistance made a difference for her family.

*I have to be off of work sometimes. I was just off that week and a half when she was in her real bad spell. So, of course, I didn't get paid when I was here. So she signed me up for these different organizations, and they helped me with my portion of the bills that I should be paying at home . . . And it was good because this next check, I only worked two days on it. So it was like, 'Okay, I don't have enough to give them for Christmas' The eight-year-old can't understand that, like, 'Well, why don't I have nothing under the Christmas tree?' But now because the social worker helped me, now I can get him something for Christmas” (Mother 1)*

## **Discussion**

Both parents and nurses overwhelmingly agreed the support that families receive from other families and children who have experienced the transplant process was the most beneficial. Although there is some research that focuses on self-care of the caregivers (Manne, Mee, Bartell, Sands, & Kashy, 2016; Lindwall et al., 2014; Burns, Robb, Phillips-Salimi, & Hoarse, 2010), parents in this study expressed more importance on the psychological aspect of their experience. They prefer socialization and support from someone who can relate to their own experiences. This is consistent with Racine et al. (2018), who piloted a support group intervention offered weekly within the hospital setting for parents of children who had a prolonged hospitalization for cancer treatment and HSCT. Parents reported lower levels of distress and the support received was relevant to their current experience because it offered a connection to other families going through the same challenges (Racine et al., 2018). Kazak et al. (2019) reported similar findings that social support is essential across the transplant trajectory, and that parents in their study needed emotional support through the course of the hospitalization.

Families described that in-person support would be the most desired, with one parent sharing that a purposeful pairing of families to provide more individualized counseling was the most helpful. Parents are confined to a single hospital room for sometimes several months, and some degree of scheduled socialization was viewed as necessary. In-person support was described as most beneficial, but this was lacking based on the findings from both the parents and the nurses. On-line support groups were a common theme described as a means for families to reach out to other families. All of the participants were in agreement that online groups provided both emotional and social support for the families and helped to connect families with the same types of underlying diagnoses. However, there were concerns about these online

groups sharing medical information, as described by one parent who was told her child was not being treated at the right institution for Fanconi's Anemia, and a nurse who shared that families don't always take the best medical advice. These concerns are consistent with a study by Coulson and Greenwood (2011), in which the investigators explored the role that online support groups play in supporting families affected by childhood cancer. Although emotional support was the primary focus of the online support groups, informational support was prominent. The authors raised concerns for the accuracy of the information being shared and with how families are using the information, including decisions about treatment options (Coulson & Greenwood, 2011).

Community support was described more by the parents than the nurses, most likely because the nurses do not see the family's resources outside of the hospital. Church, religion, and spirituality played a role in supporting families, but all of the parents only expressed their personal support structure and did not utilize the Chaplains or the hospital Chapel. This may be viewed as a very individual choice, and the hospital services are more generalized and less personal. Although some of the nurses discussed concerns for the parents' employment challenges, all of the parents shared their experiences with their employers as positive and accommodating, especially during the prolonged hospitalization of the child. Parents expressed some stress of having to work during their child's illness and more general financial concerns, but stated that they were supported in how that work gets done, including flexible scheduling. Kazak et al. (2019) reported financial concerns with families going through pediatric HSCT from more general concerns, like in our study, to more profound financial deficits such as paying for food and housing.

Only one parent shared an experience of their child being transferred to the Pediatric Intensive Care Unit (PICU), and this event was described as the most stressful time emotionally throughout the HSCT trajectory. The parent in this study described the need to connect with another parent who had been through this PICU experience to know that a child can survive these complications. When children experience complications from their HSCT such as infection, graft versus host disease, and organ toxicity, parental emotional functioning decreases, requiring critical interventions for psychosocial support (Terrin et al., 2013). The PICU experiences add to the stressors already felt by the family and include further uncertainty, helplessness, unpredictability, and hopelessness (Alzawad, Lewis, Kantrowitz-Gordon, & Howells, 2020). More research is needed to understand how to best care psychologically for the families of pediatric HSCT patients in the intensive care setting.

Family presence was viewed as crucial by both nurses and parents. Most of the parents interviewed found ways to be present, whether the parents switched off or one parent took on the role of staying with the child. One parent shared she had a lack of family support and could not be present throughout the day due to other family and work obligations, and the child shared her fears of being alone when her mom was not present. Parental activation, defined as the parents' knowledge of their child's illness and ability to manage their illness, was seen as essential in the pediatric HSCT population (Pennarola et al., 2015; Pennarola et al., 2012). Families and nurses work in harmony with each other to care for these children, so when families are not present, as described due to lack of resources, there are more challenges for the nurse to care for these children. The nurses described the challenges of not having a family presence, which include concerns psychologically for the child and not being able to stay with the unaccompanied child. Roberts (2010) reports that up to one third of hospitalized children are unaccompanied by family,

and that children are at greater risk for emotional and physical challenges when they are separated from their parents while hospitalized. Nurses experience compassion fatigue when they are caring for a child who is unaccompanied by the parents, but recognize that some parents face many obstacles to participation in their child's care (Roberts, 2010). This is consistent with the findings in our study that describes nurses are challenged when there is not a family presence, but they did acknowledge obstacles within the family that prevented visitation.

Support from the healthcare team was described very similarly in the parent and nurse interviews, and focused on the relationships formed between the families and the healthcare team. Sabo (2011) describes the meaningful relationships that stem cell transplant nurses have with their patients and families, which included the feeling of being a part of the family's lives, as they desire to help, care, and make a difference. This is consistent with the parents' experiences as they noted how nurses exceed and go above the work they do during their shift. Although the parents shared a respect for the knowledge of the HSCT team, they focused more on the continued emotional support from the provider team treating the underlying diagnosis. Often times, families have minimal contact with the HSCT team prior to the transplant because of the timeliness of this life-saving treatment, so they go into the process with little knowledge about the managing team. The nurse group talked more about the Social Worker and Child Life Specialist roles as being most beneficial, perhaps because these roles support the nurses in caring for the patients. As nurses often care for multiple patients, they don't always have time to support the families, so the Social Worker and Child Life Specialist roles were seen as family support roles that assist the nurse with their care.

Several limitations were identified that need to be acknowledged. All data were collected at a single site, which may reflect institution specific processes and challenges, and the parents

were required to be English speaking, which limits the diversity of the sample. A larger multi-site study would be more reflective of the family's experiences as a whole with the transplant process rather than specific to one institution and geographical area. Recruitment was a challenge and was gathered over a twelve-month timeframe due to two workforce disruptions at the study site and implementation of COVID-19 quarantine practices. All non-essential research was placed on hold during these three events, which resulted in limited and fragmented data collection. The nurses were interviewed earlier in the data collection period, and the parents were fragmented throughout the 12 months. The interviewer had a peripheral relationship with the nurses, however only in a support role and not managerial. The parents were also aware that the interviewer was employed at the study site, which may have impacted the parent responses. Also, during the data collection year, an in-patient HSCT nurse practitioner position was added to the care team, which reflected some of the responses from the parent group. This role was not implemented yet during the nurse interviews or the first half of the parent interviews, but parents started to comment positively on the support that they received from the HSCT team after this NP role started, which included good bridging of communication between the family and the HSCT team.

### **Practice Implications**

The face-to-face connection of one family with another going through the same experience was overwhelmingly seen as the main source for emotional support during pediatric HSCT. This particular institution, where data collection took place, as well as HSCT programs around the country should offer some kind of support group or socialization of families, which will help support these families emotionally. Lack of family presence was seen as a barrier to the HSCT experience for both the parents and the nurses. Families who have limited resources

and have challenges being present in the hospital setting should be identified prior to the HSCT so that the team can be proactive in providing support to that family. If family presence will be a challenge, a care companion can be arranged to be present with the child during crucial times throughout the prolonged hospital stay. As both nurses and parents talked about the challenges of online support groups, families may benefit from more instruction on how to navigate online support and websites, so that they are receiving the most accurate information regarding their child's illness and treatment plan.

### **Conclusion**

The pediatric HSCT experience poses many challenges for children and families, and requires a strong support structure in place to help families physically, emotionally, and psychologically. Support groups and individualized counseling from patients and families going through the same experience currently or in the past was found to be the most beneficial support intervention for families, as described by both the parents and the nurses. Parents draw upon support from their community, social resources, and family during this experience, but when these resources are lacking, the healthcare team needs to step up. This was especially evident when family presence for the hospitalized child was a challenge. The hospitalization for pediatric HSCT is the most stressful time for the family, and nurses are positioned to be the most influential support, both physically and emotionally. Gaining perspective of the stem cell transplant experience makes this study crucial in learning how to care holistically for the family during such a time of uncertainty and stress. With continued attention to the needs of the family through program evaluation and further interventional research, support during the pediatric HSCT experience can be optimized.

## **Acknowledgments**

We are grateful to The DAISY Foundation and the Society of Pediatric Nurses for their support of this research. We would like to thank the members of the Nursing Advisory Committee and James LaBelle, MD, PhD, Associate Professor of Pediatrics, and Director of the Pediatric HSCT program at the University of Chicago Medicine, Comer Children's Hospital for their contributions to the study, and the Nurse Practitioner team that helped us with recruitment. This paper is dedicated to the parents and nurses who participated in this research.



## References

- Alzawad, Z., Lewis, F.M., Kantrowitz-Gordon, I., & Howells, A.J. (2020). A qualitative study of parents' experiences in the pediatric intensive care unit: Riding a roller coaster. *The Journal of Pediatric Nursing*, 51, 8-14. <https://doi.org/10.1016/j.pedn.2019.11.015>
- Barrera, M., Atenafu, E., Doyle, J., Berlin-Romalis, D., & Hancock, K. (2012). Differences in mothers' and fathers' psychological distress after pediatric SCT: A longitudinal study. *Bone Marrow Transplantation*, 47, 934-939. doi:10.1038/bmt.2011.206
- Burns, D. S., Robb, S. L., Phillips-Salimi, C., & Haase, J. E. (2010). Parental perspectives of an adolescent/young adult stem cell transplant and a music video intervention. *Cancer Nursing*, 33(4), E20-E27. doi:10.1097/NCC.obo13e3181d4b671
- Coulson, N.S., & Greenwood, N. (2011). Families affected by childhood cancer: An analysis of the provision of social support within online support groups. *Child: Care, Health and Development*, 38(6), 870-877. doi:10.1111/j.1365-2214.2011.01316.x
- Creswell, J., & Miller, D. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39(3), 124-130. doi: 10.1207/s15430421tip3903 2
- Curtis, K., Foster, K., Mitchell, R., & Van, C. (2016). Models of care delivery for families of critically ill children: An integrative review of international literature. *Journal of Pediatric Nursing*, 31, 330-341. <http://dx.doi.org/10.1016/j.pedn.2015.11.009>
- Dempsey, L., Dowling, M., Larkin, P., & Murphy, K. (2016). Sensitive interviewing in qualitative research. *Research in Nursing and Health*, 39(1), 480-490. doi: 10.1002/nur.21743
- Department of Health and Human Services, National Institutes of Health, National Cancer Institute (2017). Childhood Cancers. Retrieved from [www.cancer.gov](http://www.cancer.gov)

- Erden, S., Kuskonmaz, B.B., Cetinkaya, D.U., Unal, F., & Ozsungur, B. (2019). Pediatric bone marrow transplantation: Psychopathologic features in recipients along with siblings. *Psycho-Oncology*, 28, 1995-2001. <https://doi.org/10.1002/pan.5179>
- Hill, R. (1949). *Families under stress: Adjustment to the crises of war separation and return*. Oxford, England: Harper.
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288. doi: 10.1177/1049732305276687
- Ingerski, L. M., Shaw, K., Gray, W. N., & Janicke, D. M. (2010). A pilot study comparing traumatic stress symptoms by child and parent report across pediatric chronic illness groups. *Journal of Developmental and Behavior Pediatrics*, 31(9), 713-719.  
Doi: 10.1097/DBP.0b013e3181f17c52
- Ishida, Y., Honda, Misato, Ozono, S., Okamura, J., Asami, K., Maeda, N., . . . Horibe, K. (2010). Late effects and quality of life of childhood cancer survivors: Part 1. Impact of stem cell transplantation. *International Journal of Hematology*, 91(5), 865-876. doi: 10.1007/s12185-010-0584-y
- Kaiser, K. (2009). Protecting respondent confidentiality in qualitative research. *Qualitative Health Research*, 19(11), 1632-1641. doi: 10.1177/1049732309350879
- Kallio, H., Pietila, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: Developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, 72(12), 2954-2965. doi: 10.1111/jan.13031
- Kazak, A.E., Swain, A.M., Pai, A.L.H., Canter, K., Carlson, O., Vega, G., & Joffe, N. (2019). Caregiver perspectives on psychosocial care in pediatric Hematopoietic stem cell transplantation (HCT). *Clinical practice in Pediatric Psychology*. Advance online

- publication. [Http://dx.doi.org/10.1037/cpp0000278](http://dx.doi.org/10.1037/cpp0000278)
- Kim, H., Sefeik, J. S., & Bradway, C. (2017). Characteristics of qualitative descriptive studies: A systematic review. *Research in Nursing and Health*, 40(1), 23-42.  
doi: 10.1002/nur.21768
- Knafl, K., & Van Riper, M. (2017). Tips for developing a successful family research proposal. *Journal of Family Nursing*, 23(4), 450-460. doi: 10.1177/1074840717743248
- Koenig, B. A., Back, A. L., & Crawley, L. M. (2003). Qualitative methods in end-of-life research: Recommendations to enhance the protection of human subjects. *Journal of Pain and Symptom Management*, 25(4), S43-S52. doi: 10.1016/So885-3924(03)00060-5
- Kolins, J., Zbylut, C., McCollom, S., & Aquino, V., (2011). Hematopoietic stem cell transplantation in children. *Critical Care Clinics of North America*, 23(2), 349-376. doi: 10.1016/j.ccell.2011.02.004
- Kronenberger, W. G., Carter, B. D., Edwards, J., Morrow, C., Stewart, J., & Sender, L. (1998). Psychological adjustment of mothers of children undergoing bone marrow transplantation: The role of stress, coping, and family factors. *Children's Health Care*, 27(2), 77-95. [https://doi.org/10.1207/s15326888chc2702\\_1](https://doi.org/10.1207/s15326888chc2702_1)
- Lahaye, M., Aujoulat, I., Vermeylen, C., & Brichard, B. (2017). Long-term effects of haematopoietic stem cell transplantation after pediatric cancer: A qualitative analysis of life experiences and adaptation strategies. *Frontiers in Psychology*, 8, 1-9. doi: 10.2289/fpsyg.2017.00704
- Lindwall, J. J., Russell, K., Huang, Q., Zhang, H., Vannatta, K., Barrera, M., . . . Phipps, S. (2014). Adjustment in parents of children undergoing stem cell transplantation. *Biology of Blood and Marrow Transplantation*, 20(4), 543-548. doi: 10.1016/j.bbmt.2014.01.007

- MacLeod, K., Whitsett, S., Mash, E., & Pelletier, W. (2003). Pediatric sibling donors of successful and unsuccessful hematopoietic stem cell transplants (HSCT): A qualitative study of their psychosocial experience. *Journal of Pediatric Psychology*, 28(4), 223-231. <https://doi.org/10.1093/jpepsy/jsg010>
- MacQueen, K., McLellan-Lemal, E., Bartholow, K., & Milstein, B. (2008). Team-based codebook development: Structure, process, and agreement. In G. Guest & K. MacQueen (Eds.), *Handbook for team-based qualitative research* (pp. 119-135). Lanham, MD: Altamira Press.
- Manne, S., Mee, L., Bartell, A., Sands, S., & Kashy, D. (2016). A randomized clinical trial of a parent-focused social-cognitive processing intervention for caregivers of children undergoing hematopoietic stem cell transplantation. *Journal of Consulting and Clinical Psychology*, 84(5), 389-401. doi: 10.1037/ccp0000087
- Mayer, D. K., Tighiouart, H., Terrin, N., Stewart, S., Peterson, E., Jeruss, S., & Parsons, S. K. (2009). A brief report of caregiver needs and resource utilization during pediatric hematopoietic stem cell transplantation. *Journal of Pediatric Oncology Nursing*, 26(4), 223-229. doi:10.1177/1043454209340409
- Mayer, D. K., Ratichek, S., Berhe, H., Stewart, S., McTavish, F., Gustafson, D., & Parsons, S. K. (2010). Development of a health-related website for parents of children receiving hematopoietic stem cell transplant: HSCT-CHESS. *Journal of Cancer Survivorship*, 4, 67-73. doi: 10.1007/s11764-009-0108-z
- Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal*, 320(7226), 50-52. doi: 10.1136/bmj.320.7226.50

- McCabe, J. L., & Holmes, D. (2009). Reflexivity, critical qualitative research and emancipation: A Foucauldian perspective. *Journal of Advanced Nursing*, 65(7), 1518-1526. doi: 10.1111/j.1365-2648.2009.04978.x
- McCubbin, H. I., Cauble, A. E., & Patterson, J. M. (1982). *Family stress, coping and social support*. Springfield, Illinois: Charles C. Thomas Publisher.
- McCubbin, H. I. , & McCubbin, M. A. (1993). Families coping with illness: The resiliency model of family stress, adjustment, and adaptation. In C. B. Danielson, B. Hamel-Bissell, & P. Winstead-Fry (Eds.), *Families, health, & illness: Perspectives on coping and intervention* (21-63). St. Louis, Missouri: Mosby.
- McCubbin, H. I., Thompson, A. I., & McCubbin, M. A. (1996). *Family assessment: Resiliency, coping and adaptation: Inventories for research and practice*. Madison, Wisconsin: University of Wisconsin Publishers.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). New York: Sage Publications, Inc.
- Norberg, A., Mellgren, K., Winiarski, J., & Forinder, U. (2014) Relationship between problems related to child late effects and parent burnout after pediatric hematopoietic stem cell transplantation. *Pediatric Transplantation*, 18, 302-309. doi: 10.1111/petr.12228
- O'Reilly, M., & Parker, N. (2012). Unsatisfactory saturation: A critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research*, 13(2), 190-197. doi: 10.1177/1468794112446106
- Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The Qualitative Report*, 13(4), 695-705. <https://nsuworks.nova.edu/tqr/vol13/iss4/8>

- Packman, W., Gong, K., VanZutphen, K., Shaffer, T., & Crittenden, M. (2004). Psychological adjustment of adolescent siblings of hematopoietic stem cell transplant patients. *Journal of Pediatric Oncology Nursing*, 21(4), 233-248. doi: 10.1177/1043454203262698
- Parsons, S. K., DuHamel, K. N., Ostroff, J., Mayer, D. K., Austin, J., Martini, D. R., Manne, S. (2006). Maternal perspectives on children's health-related quality of life during the first year after pediatric hematopoietic stem cell transplant. *Journal of Pediatric Psychology*, 31(10), 1100-1115. doi: 10.1093/jpepsy/jsj078
- Patton M. Q. (2015). Qualitative designs and data collection. Module 38: Mixed, stratified, and nested purposeful sampling strategies. *Qualitative Research & Evaluation Methods*. 4th ed. Thousand Oaks, CA: Sage Publications, Inc: 305-307.
- Peacock, N., & Paul-Ward, A. (2006). Contemporary tools for managing and analyzing qualitative data. In G. Kielhofner (Ed.), *Research in Occupational Therapy: Methods of Inquiry for Enhancing Practice* (pp. 358-371). Philadelphia, PA: F.A. Davis, Co.
- Pennarola, B. W., Rodday, A. M., Mayer, D. K., Ratichek, S. J., Davies, S. M., Syrjala, K. L., Patel, S., Bingen, K., Kupst, M.J., Schwartz, L., Guinan, E.C., Hibbard, J.H., & Parsons, S. K. (2012). Factors associated with parental activation in pediatric hematopoietic stem cell transplant. *Medical Care Research and Review*, 69(2), 194-214. doi: 10.1177/1077558711431460
- Pennarola, B.W., Rodday, A.M., Bingen, K., Schwartz, L.A., Patel, S.K., Syrjala, K.L., Mayer, D.K., Ratichek, S.J., Cuinan, E.C., Kupst, M.J., Hibbard, J.H., & Parsons, S.K. (2015). Changing factors associated with parent activation after pediatric hematopoietic stem cell transplant. *Supportive Care in Cancer*, 23, 1997-2006. doi: 10.1007/s00520-014-2544-1

- Pentz, R.D., Alderfer, M.A., Pelletier, W., Stegenga, K., Haight, A.E., Hendershot, K.A., Dixon, M., Fairclough, D., & Hinds, P. (2014). Unmet needs of siblings of pediatric stem cell transplant recipients. *Pediatrics*, 133(5), 1156-1162. <https://doi.org/10.1542/peds.2013-3067>
- Racine, N.M., Smith, A., Pelletier, W., Schoot-Lane, L., Guilcher, G.M.T., & Schulte, F. (2018). Evaluation of a support group for parents of children hospitalized for cancer and hematopoietic stem cell transplantation. *Social Work With Groups*, 41(4), 276-290. <https://doi.org/10.1080/01609513.2017.1356799>
- Riva, R., Forinder, U., Arvidson, J., Mellgren, K., Toporski, J., Winiarski, J., & Norberg, A. (2014). Patterns of psychological responses in parents of children that underwent stem cell transplantation. *Psycho-Oncology*, 23, 1307-1313. doi:10.1002/pon.3567
- Roberts, C.A. (2010). Unaccompanied hospitalized children: A review of the literature and incidence study. *Journal of Pediatric Nursing*, 25, 470-476. doi: 10.1016/j.pedn.2009.12.070
- Rowan, C., Gertz, S., McArthur, J., Fitzgerald, J., Nitu, M., Loomis, A., . . . Tamburro, R. (2016). Invasive mechanical ventilation and mortality in the pediatric hematopoietic stem cell transplantation: A multicenter study. *Pediatric Critical Care Medicine*, 17(4), 294-302. doi: 10.1097/PCC.0000000000000673
- Sabo, B. M. (2011). Compassionate presence: The meaning of hematopoietic stem cell transplant nursing. *European Journal of Oncology Nursing*, 15(1), 103-111. doi: 10.1016/j.ejon.2010.06.006
- Sandelowski, M. (1993). Theory unmasked: The uses and guises of theory in qualitative research. *Research in Nursing & Health*, 16, 213-218. doi: 10.1002/nur.4770160308

- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health*, 23, 334-340. doi:10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g
- Santacroce, S. J. (2003). Parental uncertainty and posttraumatic stress in serious childhood illness. *Journal of Nursing Scholarship*, 35(1), 45-51. doi: 10.1111/j.1547-5069.2003.00045.x
- Seidman, I. (2013). *Interviewing as qualitative research: A guide for researchers in education & the social sciences* (4<sup>th</sup> Ed.). New York, NY: Teachers College Press.
- Tanzi, E. M. (2011). Health-related quality of life of hematopoietic stem cell transplant childhood survivors: State of the science. *Journal of Pediatric Oncology Nursing*, 28(4), 191-202. doi: 10.1177/1043454211408100
- Terrin, N., Rodday, A., Tighiouart, H., Chang, G., & Parsons, S. (2013). Parental emotional functioning declines with occurrence of clinical complications in pediatric hematopoietic stem cell transplant. *Support Care in Cancer*, 21, 687-695. doi: 10.1007/s00520-012-1566-9
- Ulin, P., Robinson, E., & Tolley, E. (2005). *Qualitative methods in public health: A field guide for applied research*. San Francisco, CA: Jossey-Bass.
- van der Geest, I., Darlington, A. S., Streng, I., Michiels, E., Pieters, R., & van den Heuvel-Eibrink, M. M. (2014). Parents' experiences of pediatric palliative care and the impact on long-term parental grief. *Journal of Pain and Symptom Management*, 47(6), 1043-1053. doi: 10.1016/j.jpainsymman.2013.07.007
- van Walraven, S.M., Ball, L.M., Koopman, H.M., Switzer, G.E, Ropes-de Jong, C.M.H., de Jong, A., Bredius, R.G.M., & Egeler, R.M. (2012). Managing a dual role – Experiences and coping strategies of parents donating haploidentical G-CSF mobilized peripheral



- blood stem cell to their children. *Psycho-Oncology*, 21, 168-175. doi: 10.1002/pon.1885
- Virtue, S. M., Manne, S. L., Mee, L., Bartell, A., Sands, S., Gajda, T. M., & Darabos, K. (2014a). Psychological distress and psychiatric diagnoses among primary caregivers of children undergoing hematopoietic stem cell transplant: An examination of prevalence, correlates, and racial/ethnic differences. *General Hospital Psychiatry*, 36, 620-626. doi: 10.1016/j.genhosppsych.2014.08.010
- Virtue, S. M., Manne, S., Mee, L., Bartell, A., Sands, S., Ohman-Strickland, P., & Gajda, T. M. (2014b). The role of social and cognitive processes in the relationship between fear network and psychological distress among parents of children undergoing hematopoietic stem cell transplantation. *Journal of Clinical Psychology in Medical Settings*, 21, 223-233. doi: 10.1007/s10880-014-9403-6
- Weber, J. G. (2011). Individual and family stress and crises. Thousand Oaks, California: SAGE Publications, Inc.
- White, T., Hendershot, K. A., Dixon, M., Pelletier, W., Haight, A., Stegenga, K., . . . Pentz, R. (2017). Family strategies to support siblings of pediatric hematopoietic stem cell transplant patients. *Pediatrics*, 139(2). doi: 10.1542/peds.2016-1057.
- Wilkins, K., & Woodgate, R. (2007a). An interruption in family life: Siblings' lived experience as they transition through the pediatric bone marrow transplant trajectory. *Oncology Nursing Forum*, 34(2), 28-35. doi: 10.1188/07.ONF.E28-E35
- Wilkins, K., & Woodgate, R. (2007b). Supporting siblings through the pediatric bone marrow transplant trajectory: Perspectives of siblings of bone marrow transplant recipients. *Cancer Nursing*, 20(5), 29-34. doi: 10.1097/01.NCC.0000290811.06948.2c

Young, L. (2013). The family experience following bone marrow or blood cell transplantation.

*Journal of Advanced Nursing*, 69(10), 2274-2284. doi: 10.1111/jan.12111

Zinter, M., Dvorak, C., Spicer, A., Cowan, M., & Sapru, A. (2015). New insights into multicenter PICU mortality among pediatric hematopoietic stem cell transplant patients.

*Critical Care Medicine*, 43(9), 1986-1994. doi: 10.1097/CCM.0000000000001085

Table 1

*Family Support Inclusion and Exclusion Criteria: Parent and Nurse*

<b>Inclusion Criteria: Parent</b>	<b>Inclusion Criteria: Nurse</b>
Parent/caregiver is English speaking and $\geq$ 18 years of age	Pediatric oncology/HSCT nurse who is off orientation
Child is hospitalized for a HSCT – can be subsequent transplants if they are enrolled in a protocol that requires more than one transplant	Pediatric oncology/HSCT nurse who has worked at the study institution for 6 months
Primary parent of the child – actively involved with the care of the child in the hospital setting	Pediatric oncology/HSCT nurse who cared for a HSCT patient within the last 2 months
Autologous or allogeneic transplant for any disease process – malignant or non-malignant (efforts will be made to recruit both)	Willing to participate in the study and provide one interview at one time point
Parent willing to participate in one interview at one time point towards the end of the hospitalization time frame – optional follow-up interview at least 24 hours after the first interview while the child is still hospitalized	Nurses who work any shift – including dayshift, nightshift, or rotating shift – efforts will be made to recruit different shifts to be represented
Patient has not died or is not imminently dying – admission to the PICU will not be excluded	
<b>Exclusion Criteria: Parent</b>	<b>Exclusion Criteria: Nurse</b>
Parent who requires a translator to communicate and/or is $<18$ years of age	Pediatric oncology/HSCT nurse who is currently in orientation to the inpatient care unit
Child is readmitted for complications after discharge home for HSCT	Pediatric oncology/HSCT nurse who has not worked at the study institution for 6 months
Parent not present during the hospitalization for the child's HSCT	Pediatric Oncology/HSCT nurse has not cared for a HSCT patient in the past 2 months
Child is critically ill in the PICU setting or deemed terminal	Float nurses and registry nurses not based on the in-patient pediatric oncology unit

Table 2

*Family Support Interview Guide: Example Questions*

<i>Parent Interview Questions (First Interview)</i>
<ol style="list-style-type: none"> <li>Introductory Questions: <ul style="list-style-type: none"> <li>Describe your child's disease, when he/she was diagnosed, and what that was like?</li> <li>Describe the experience of learning that your child would require a HSCT?</li> <li>How did you prepare for your child's transplant? How did the healthcare team prepare you for this journey?</li> </ul> </li> </ol>
<ol style="list-style-type: none"> <li>Are there resources within your <b>community</b> that you draw support from throughout this hospitalization? (Schools, church, employers, foundations, community)</li> </ol>
<ol style="list-style-type: none"> <li>What is/are your biggest <b>social</b> resource(s) when you just need to talk to someone throughout this hospitalization? (friends, social media, support group)</li> </ol>
<ol style="list-style-type: none"> <li>Have there been <b>family</b> members who have provided support to you during your child's hospitalization? If so, how have they helped you?</li> </ol>
<ol style="list-style-type: none"> <li>What support by the <b>healthcare team</b> has been most beneficial to you? (nurses, physicians, social work, child life, programs) <ul style="list-style-type: none"> <li>How have your nurses supported you? Physicians? Other services?</li> <li>Is there anything missing or that can be strengthened?</li> </ul> </li> </ol>
<i>Parent Interview Questions (Second Interview)</i>
<ol style="list-style-type: none"> <li>Is there anything that you have thought about since our first meeting that you wanted to discuss or clarify?</li> </ol>
<ol style="list-style-type: none"> <li>Do you have additional thoughts that you want to add about your hospitalization experience?</li> </ol>
<i>Nurse Interview Questions</i>
<ol style="list-style-type: none"> <li>What have you experienced as the most influential <b>community</b> resources that families draw upon during their child's hospitalization for transplant?</li> </ol>
<ol style="list-style-type: none"> <li>What have you experienced as the family's greatest <b>social</b> resource during the child's hospitalization? Who is/are the biggest resource(s) when families need to talk to someone throughout this hospitalization?</li> </ol>
<ol style="list-style-type: none"> <li>What have you experienced as support for transplant families from other <b>family</b> members and what has been their role?</li> </ol>
<ol style="list-style-type: none"> <li>What support within the hospital is most beneficial to the family during their hospitalization for transplant?</li> </ol>
<ol style="list-style-type: none"> <li>How does the <b>healthcare team</b> support families during HSCT hospitalization?</li> </ol>
<ol style="list-style-type: none"> <li>How do you support the families through the HSCT experience? Is there anything missing or that can be strengthened?</li> </ol>
<ol style="list-style-type: none"> <li>What support interventions would you like to see in place to help the child and the family with the transplant experience?</li> </ol>

Table 3

*Family Support Parent Demographic Data: N=10*

<b>Variable</b>	<b>Count (%)</b>
<b>Gender:</b> Female	6(60%)
Male	4(40%)
<b>Race/Ethnicity</b>	
White/Caucasian	7(70%)
Black/African American	3(30%)
<b>Education</b>	
High School Diploma	2 (20%)
Trade School	2 (20%)
Associates Degree	2 (20%)
Baccalaureate Degree	3 (30%)
Masters Degree	1 (10%)
<b>Employment Status</b>	
Full-time	6 (60%)
Self-Employed	2 (20%)
Unemployed	1 (10%)
Other	1(10%)
<b>Married Status</b>	
Married	10 (100%)
<b>Type of Transplant</b>	
Autologous	3(50%)
Allogeneic	
Sibling Donor	1 (17%)
Parent Donor/Haplo	1 (17%)
Matched Unrelated Cord	1 (17%)
<b>Disease</b>	
Hodgkins Lymphoma (Auto)	2 (40%)
Congenital Neutropenia (Allo)	1 (17%)
Neuroblastoma (Auto)	1 (17%)
Fanconi's Anemia (Allo)	1 (17%)
MDS - Post ALL (Allo)	1 (17%)
<b>Family Role</b>	
Stay with child	2 (20%)
Work	1 (10%)
Both (stay/work)	7 (70%)
<b>Variable</b>	<b>Mean(yrs)</b> <b>Range(yrs)</b>
Age (parent)	41.9            30 to 56
Age (child)	11.2            3 to 19

Table 4

*Family Support Nurse Demographic Data N=15*

Variable	Count (%)
<b>Gender:</b>	
Female	15(100%)
<b>Race/Ethnicity</b>	
White/Caucasian	9(60%)
Asian	2(13%)
Black/African American	2(13%)
Latino/Hispanic	1(7%)
Other	1(7%)
<b>Highest Nursing Education</b>	
Baccalaureate (BSN)	15 (100%)
Masters (MSN)	3(20%)
<b>Shift</b>	
Dayshift	8(53%)
Nightshift	7(47%)
<b>Specialty Certification</b>	
Yes	6(40%)
No	9(60%)
<b>Role on the Unit</b>	
Staff Nurse	15(100%)
Charge Nurse	10(67%)
Preceptor	7(47%)
<b>Training Received</b>	
SCT Class	13(86%)
Computer Modules	1(7%)
Experience	1(7%)
<b>Variable</b>	<b>Mean(yrs)</b> <b>Range (yrs)</b>
Age	37 26 to 62
Years as a Nurse	13.1 3 to 37
Years as an Oncology Nurse	9.7 1.5 to 28

Table 5

*Sample Quotations: Family Support*

<b>Theme</b>	<b>Subtheme</b>	<b>Quote</b>
<b><i>Community Support</i></b>	<i>Church/Religion/Spirituality</i>	“We honestly never went to a church, but even the churches around us have donated, dropped off gift baskets and gift cards” (Mother 5).
	<i>Foundations</i>	“There’s something in Northwest Indiana called The NIC Foundation . . . they usually deal with kids that have cancer, but he’s got such a rare disease that is treated with chemo . . . they sent us tons of gifts, gift cards, and an Amazon gift care” (Mother 5)
	<i>Community</i>	“So the amount of support we’ve gotten from our community has been overwhelming. And if there’s anything that’ll get me crying, it’s that” (Father 3)
	<i>Work</i>	“Our jobs have been great . . . money hasn’t been an issue because we’ve been getting paid, and our insurance has been wonderful . . . My company was good. Even though they’re anti-working from home, they’ve been letting me. Since this all happened, I’ve been able to work from home so that I can get him back and forth . . . I’m an accountant, so it’s an easy thing to do” (Mother 3)
	<i>School</i>	<p>“ . . . we had the hospital write up a note. And we had them include that he was being a hero in the note. So his teacher, she just read it to the class and the let the class know that he was busy being a hero” (Mother 2)</p> <p>“His school had a fundraiser. They made T-shirts, and they their T-shirts every Monday . . . Friday is a spaghetti dinner through the high school – people in this town are probably like, ‘God, that name again’” (Mother 5).</p>
<b><i>Social Support</i></b>	<i>Support Group</i>	<p>(Emotional Support) “Both their kids were here. Both diagnosed with neuroblastoma. Both from not around here and they had connected on a Facebook page and noticed one posted a photo . . . they realized that they were down the hall from each other, but the parents had no idea that they were communicating online” (Nurse 14)</p> <p>(Questionable medical advice) “Our course of therapy is always to have a transplant, a double one. And I think three families opted not to do the transplants based off of</p>

		<p>information that they received from other families with kids of neuroblastoma . . . they get information that way, education that way” (Nurse 9)</p> <p>(Less encouraging) “There’s been at least three other families that we’ve chatted with to varying degrees who also have children with neuroblastoma. One actually died right before her year anniversary from her diagnosis . . . The other family went through a year of treatment . . . and then 3 months later, got re-diagnosed again, all widespread, and then that boy just died a few months ago” (Father 4)</p> <p>(Support Intervention) “They do a lot of stuff for the kids, but there’s not a whole lot of - - or easier things for the parents . . . If someone came and did haircuts . . . you’re stuck in here, and there’s not a whole lot for the parents to feel sane” (Mother 5).</p>
	<i>Social Media</i>	<p>“Somebody once said, ‘oh, start a Facebook page . . . you send out these updates, then people won’t ask’. I don’t think that’s true because I know people who have Facebook pages who update it, and you’re still asking them every time you see them because you’d feel rude if you don’t . . . I’ve tried to kind of retreat from social stuff a bit, some for logistic reasons, like while he’s here or while he’s not feeling well, and then other times, just because you don’t feel like going anywhere to have to hash it all out again” (Mother 6)</p>
	<i>Friends</i>	<p>“I got a friend that I talk to if I have to vent or let out some things, a friend to talk to but physically, helping me out, it’s just me” (Mother 1).</p>
	<i>Ronald McDonald House (RMH)</i>	<p>“It’s almost like a forced support group thing that you didn’t know you’d be a part of” (Nurse 15).</p>
<b>Family Support</b>	<i>Grandparents</i>	<p>“My husband mother, she’s come up here and sat with him. My mother, she’s come up here and sat with him. Just to take a break or just because they miss him too – ‘Let me come up there and see him when you all go do what you all need to do. I know you miss your husband’. So sometimes we do be needing that special time to see and talk to each other, make sure everything is good with each other. Family</p>

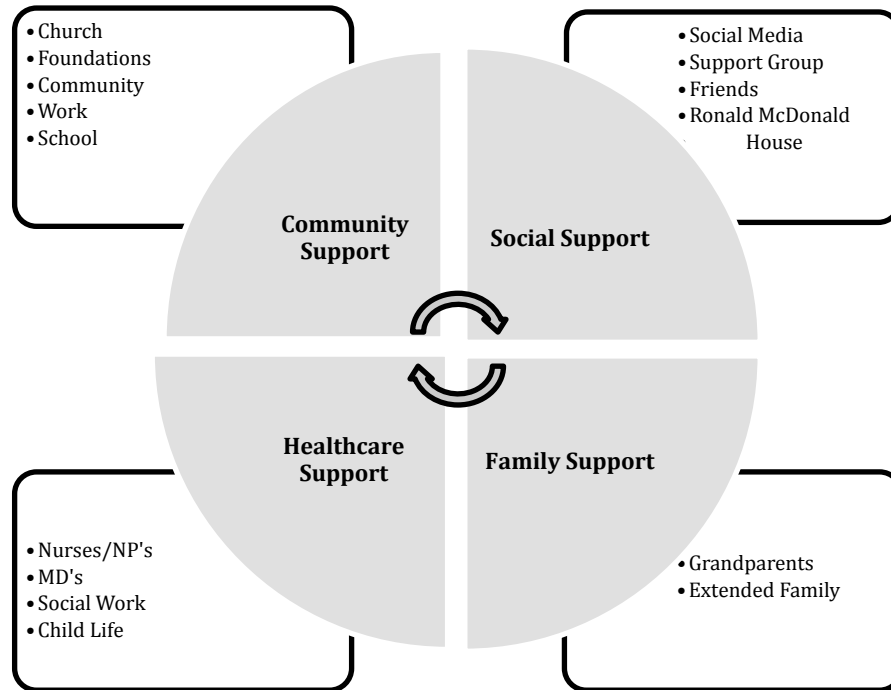


		has definitely been the biggest support” (Mother 2)
	<i>Extended Family</i>	“They rely on other family members to help with their other children, the extended family” (Nurse 6)
	<i>Lack of Support</i>	<p>“The only thing I can really think of is when the parents aren’t here with the child during a transplant. Sometimes, we have to emotionally be there for the child because they’re asking for their mom or dad, and there’s no one here with them. And we can’t always be in the room with them, and it kind of hurts to leave, and they’re in there crying . . .</p> <p>Sometimes, we have another transplant patient we have to take care of as well – so we have to juggle two at a time during our shift” (Nurse 2)</p>
<b>Healthcare Support</b>	<i>Nurse</i>	<p>“She comes in the room and says, ‘I’ve got to be on the fourth floor today . . . Don’t worry, I’m watching the counts. I’ll come back’. And sure enough, two hours later, I was on a conference call, she walks in the room, she gives a big thumbs up. I’m like, “well, she did follow up. How cool is that?” (Father 3).</p> <p>(Respite care) “I can always tell when a family member, a parent, needs a mental break, needs to step away. I’ll always encourage them to go out and get something to eat, go for a walk. I can pass my phone off to someone and I’ll sit in here” (Nurse 9)</p> <p>“I think just getting to know them and making it seem like it’s not a big deal to help them with things . . . A lot of families are so nice too. They don’t want to ask for things” (Nurse 15).</p>
	<i>Nurse Practitioner</i>	<p>“We have our stem cell nurse who’s like our everyday go-to” (Mother 6).</p> <p>“The outpatient oncology NP, I call her the guardian angel. She’s just amazing throughout everything, anytime we had a question or just making us feel better about things or giving us a hug or whatever. I mean, she is just unbelievable . . . She just has that way of making you feel calmer” (Mother 3)</p>
	<i>Physician</i>	“The most impressive doctor that we’ve talked to is the Chief of the stem cell program, just

		so far as his knowledge and he's a very good communicator. You can tell he's good with people and he really knows his medicine too" (Father 4).
	<i>Child Life Specialist</i>	<p>"Child Life would be very helpful at night because sometimes our children are up close to midnight, and they are just asking, 'Can you come play with me?' And sometimes we can't always sit in there because we do have other patient" (Nurse 2)</p> <p>"Volunteers are a huge support system for us. Like patients who are four and just at risk of pulling out their central line or just falling and bleeding. Any time we can get a volunteer, it's a huge help" (Nurse 4).</p>
	<i>Social Worker</i>	"I know a lot of times when they (parents) have questions that the team can't specifically answer, and it's something I know that the social worker usually steps in and they have multiple resources. Whether it be giving them bus passes to go from here to wherever they need to be, or meal vouchers or parking vouchers . . . they (SW) can come here and the parents know that their concerns are kind of being answered" (Nurse 14)

Figure 1

*Pediatric HSCT Family Support Model*



*Note:* The strongest family support throughout the acute phase of the pediatric HSCT experience includes a combination of those from the healthcare team, community, family, and social resources working together to help maintain family resilience.

## **II. PARENTAL STRESSORS, COPING, AND ADAPTATION RELATED TO THE PEDIATRIC HEMATOPOIETIC STEM CELL TRANSPLANT (HSCT) EXPERIENCE: PERSPECTIVES FROM PARENTS AND NURSES**

Over 20,000 children, adolescents, and young adults (0-30 years) received a life-saving hematopoietic stem cell transplant (HSCT) for life-threatening pediatric conditions between 2013 and 2017 in the United States, and this number continues to climb with the advancement of new cellular therapies (Donation and Transplantation Statistics, 2020). Children receive allogeneic HSCT, infusion of donor cells, and autologous HSCT, infusion of cryopreserved cells from the patient, for hematologic and solid tumor malignancies, anemia conditions, and immunologic and metabolic conditions (Kolins, Zbylut, McCollom, & Aquino, 2011). Although autologous HSCT is associated with fewer complications, the underlying diseases that accompany autologous HSCT tend to be very complex, with significant mortality rates. Pediatric HSCT overall is associated with a 35% mortality rate at one year with infection, organ toxicity, and graft versus host disease as the most experienced complications. Morbidity brought on by acute and chronic complications leads to significant psychological challenges of both the child and the family (National Cancer Institute, 2017; Balit et al., 2016). Because of the reported mortality rates associated with pediatric HSCT, prolonged hospitalizations, and uncertainty related to the prognosis of outcomes, most of the families of these children suffer significant psychological effects surrounding pediatric HSCT.

### **Background**

Children exhibit significant acute and chronic physical and psychological effects after pediatric HSCT, which affect family functioning (Lahaye, Aujoulat, Vermynen, & Brichard, 2017). Physical dysfunction, psychological stress, and social adaptation problems were observed

in over 70% of children who were treated with HSCT and include infection, organ toxicity, graft versus host disease, pain, nausea, fatigue, anxiety, depression, social dysfunction, body image concerns, and dissatisfaction with family life (Ishida, et al., 2010; Tanzi, 2011; Lahaye et al., 2017). The siblings and sibling donors also face significant challenges as the child and family experience HSCT. Donor siblings face several emotions, including fear of the donation process and guilt if the child has a poor outcome (MacLeod, Whitsett, Mash, & Pelletier, 2003; Wiener et al., 2008; Hutt et al., 2015; Switzer et al., 2016). Most siblings, however, do welcome the opportunity to donate to the sick child, and the donation process contributes positively to their emotional and social development by allowing them to participate with the child's treatment (D'Auria et al., 2014; Pentz et al., 2014; Wilkins & Woodgate, 2007a). Both donor and non-donor siblings have a reported interruption in family life, and feel they should be included in the family as much as possible, have choices, be given information, have a defined role, and have individual time with the family and the sick child (Wilkins & Woodgate, 2007b; White et al., 2017; Erden, Kuskonmaz, Cetinkaya, Unal, & Ozsungur, 2019; Wilkins & Woodgate, 2007a; Packman, Gong, VanZutphen, Shaffer, & Crittenden, 2004).

It is well known that parents face increased psychological distress as their child enters the HSCT phase of their treatment (McDowell, Titman, & Davidson, 2010; Barrera, Atenafu, Doyle, Berline-Romalis, & Hancock, 2012; Forinder, Posse, & Winiarski, 2008). Posttraumatic stress disorder (PTSD) is reported in over 50% of parents during the acute phase of the HSCT experience (first three months), with 15% of parents reporting PTSD five years after the transplant (Virtue et al., 2014; Riva et al., 2014). Parental burnout and anxiety are also common psychological effects seen with pediatric HSCT, most often related to the prolonged course of HSCT and uncertainty of outcomes (Norberg, Mellgren, Winiarski, & Forinder, 2014; Norberg

& Forinder, 2016). Life-threatening patient complications were seen to decrease parental emotional functioning, adding to the psychological distress (Terrin, Rodday, Tighiouart, Chang, & Parsons, 2013). Parents are often stem cell donors for their child, posing different psychosocial challenges for the parents and include fear, helplessness, and self-blame if the child has a poor outcome (van Walraven et al., 2012). Finally, traumatic stress symptoms tend to be higher in the families whose child was a HSCT candidate than in other populations of childhood chronic illness, indicating the stress that HSCT has on the family (Ingreski, Shaw, Gray, & Janicke, 2010; Drew, Goodenough, Maurice, Foreman, & Willis, 2005).

Coping and adaptation strategies to pediatric illness have been illustrated in the research, but very little focuses on the pediatric HSCT population specifically during the acute phase while the child is hospitalized. Parental activation is described as a necessary adaptation method for families involved with pediatric HSCT and is defined as parental knowledge of their child's illness and active participation in their care (Pennarola et al., 2012; Pennarola et al., 2015). Because of the rigorous regimen and prolonged trajectory of HSCT treatment, parental involvement in the child's care remains vital to the success of the child's well-being as well as maintaining the family cohesiveness. Parents were found to improve their adjustment to their child's HSCT over time, however it is noted there is a time of elevated distress during the child's hospitalization and when the child experiences complications at any point during the first year, parental emotional functioning is impacted (Lidwall et al., 2014; Terrin et al., 2013). Some parental coping strategies have been defined and include: talking with family and friends, optimism, praying, and being informed (Cavadini et al., 2019). Parents need to be informed and express their emotions as they relate to hope and fear and transplant outcome (van Walraven, et al., 2012). A lack of adaptation to the child's HSCT experience is noted in parents who don't

find social outlets for their emotions (Virtue et al., 2014). Uncertainty can be a significant factor that contributes to the psychological stress and anxiety of parents when their children face serious illness. The sources of uncertainty stem from diagnosis, daily activity, interactions, and future outlook, which can lead to posttraumatic stress on the parents (Santacroce, 2003; Hinton & Kirk, 2017). Parental uncertainty is linked to a negative impact on coping strategies, including the interaction with other family members (Lin, Yeh, & Mishel, 2010). Parental coping and adapting strategies are key to maintain family functioning during this time of crisis.

Pediatric HSCT is a complex process that impacts the family as a whole. Although care of the child's life-threatening illness is the priority, many needs and challenges arise with the family dynamic throughout the HSCT experience that should be addressed (Kazak et al., 2019). There is a significant gap in the literature outlining interventions for families while the child is hospitalized for HSCT. This qualitative descriptive study describes the factors that are most stressful and challenging for the parents of children who have undergone HSCT and explores how parents cope and adapt to their stressors. Understanding the stressors of pediatric HSCT and parental coping and adaptation, particularly during the child's hospitalization for HSCT when the parents stress levels are highest, will assist the healthcare team develop supportive interventions that address the needs within the family.

## **Methods**

### **Design**

This study design used a qualitative descriptive approach to capture the experiences of both the parents and nurses in describing the stressors, coping mechanisms, and adaptation that families face during their child's hospitalization for pediatric HSCT (Kim, Sefcik, & Bradway, 2017; Sandelowski, 2010).

## **Sample**

A stratified purposeful sampling method (Patton, 2015) and eligibility criteria (Table 6) were used to recruit parents of children who underwent a HSCT and nurses from a pediatric oncology inpatient unit. Parents were defined as not only the biological parents, but as the legal parent/guardian or designated caregiver (Knafl & Van Riper, 2017). The sample size for this study was consistent with other similar studies that evaluated the pediatric HSCT experience (Kim et al., 2017) and data saturation was reached at 12 nurses and 10 parents (O'Reilly & Parker, 2012; Ulin et al., 2005). Parents were recruited by the HSCT team, either during a clinic visit or after admission for the transplant procedure. Flyers and informational staff meetings were used to recruit the nurses.

## **Measures**

The parents completed a demographic survey, a required semi-structured interview within one week from discharge while the child was still hospitalized, and an optional second semi-structured interview (Table 7). The second optional interview was completed at least 24 hours after the first interview, but prior to discharge (Dempsey, Dowling, Larkin, & Murphy, 2016; Seidman, 2013). Parents were interviewed separately to identify role differences (Kronenberger et al., 1998; LoBiondo-Wood, Williams, & McGhee, 2004; Barrera et al., 2012; Parsons et al., 2006) and nurses were interviewed within two months of caring for a transplant patient to capture their perspectives on the general pediatric HSCT population.

## **Procedures**

After approval from the Institutional Review Board (IRB: 19-0308), data collection began at a large urban academic medical center in the Midwest. Participants were consented and interviewed privately, face-to-face, and at the convenience of the participant. Interviews were



audio-recorded, transcribed verbatim, checked for accuracy, and compared to the field notes taken. A Nurse Advisory Committee, consisting of non-research participants from the pediatric oncology unit, provided input to the interview guides, reviewed the themes, and contributed to a dissemination plan. All participants received a small token for participation as outlined in the grant proposals (\$30.00 gift card for the first interview; \$15.00 for the second interview). Confidentiality was ensured and a safety-monitoring plan was developed and in place to address any psychological distress from the parent and nurse participants (Koenig, Back, & Crawley, 2003; Kaiser, 2009).

## **Analysis**

A directed content analysis approach was used, which incorporated predetermined codes to assist in the validation of the conceptual framework (Hsieh & Shannon, 2005; MacQueen, McLellan-Lemal, Bartholow, & Milstein, 2008). Stressors, coping, and adaptation were outlined as the overarching themes in which subthemes emerged. Stressors were defined as demands on the family that may potentially change the family functioning; coping describes individual or family effort to decrease the stressful event, including the incorporation of resources; and adaptation describes the outcome of the efforts to manage a stressful situation, or what families have done to change in response to the stressor. Data were reduced and displayed using the matrix method, leading to thematic conclusions, and NVivo 12 for Mac organized the data for analysis (Miles & Huberman, 1994; Peacock & Paul-Ward, 2006; Ulin et al., 2005). Dependability was sustained by using a team approach for the analytic process, and the codes were monitored for drift by keeping them well defined. Member checking established credibility by reviewing the meaning of the interviews and themes with two nurses, and triangulation of

views between the nurses and parents helped with convergence among the different data sources (Creswell & Miller, 2000; Ortlipp, 2008; Mays & Pope, 2000).

### **Conceptual Framework**

The design, measures, analysis, and summation of this study were guided by an adaptation from the *Resiliency Model of Family Stress, Adjustment, and Adaptation* (Hill, 1949; McCubbin et al., 1996; McCubbin & McCubbin, 1993; McCubbin, Gauble, & Patterson, 1982; Weber, 2011). This adapted framework identifies a family stressor that leads to coping and adaptation with the assistance of various support methods socially, from the community, from the family, and from the healthcare team. Stressors of pediatric HSCT, coping mechanisms, and adaptation were the concepts incorporated into the semi-structured interview questions (Kallio, Pietila, Johnson, & Kangasniemi, 2016), and were used for the directed content analysis and summation (Figure 2).

### **Results**

Ten parents (n=10) from six families and fifteen nurses (n=15) participated in the study. Each participant completed a demographic survey and one semi-structured interview, and two parents completed an optional second interview (Table 8 & Table 9). The other eight parent participants were either discharged within 24 hours of the first interview or declined the second interview. The parent interviews were between 20(min):39(sec) to 56:08 (mean 37:28) for the first interview; 3:07 to 7:17 (mean 5:15) for the second interview. The nurse interviews were between 13:08 to 51:37 (mean 26:29). The directed content analysis of the data yielded several subthemes that arose from the primary themes of stressors, coping, and adaptation, and are outlined below (Table 10).

## **Stressors**

The subthemes that emerged as stressors for the parents include: family obligations, seeing the child sick, work/financial obligations, marital stress, sleep deprivation, lack of information, transplant-related complications, prolonged hospitalization, and single room isolation.

### ***Family Obligations***

Tending to family obligations was one of the strongest subthemes that emerged from the parent and nurse interviews. Parents described having to take turns being at the hospital so that the other parent can be home, and that other family obligations were often neglected. One parent dyad also shared different perceptions of the sibling experiences, in which the mother was more concerned than the father about the sibling being home alone or with other family members (Table 5). Another mother shared the disruption that the HSCT experience can cause within the family structure, especially with the younger sibling. However, the father described the sibling's experience more positively.

*Biggest challenge is, definitely with us, just trying to keep all the balls juggling that we normally juggle anyway. Even before the cancer stuff, been very busy with eight kids . . . My wife and I pretty much switch every three to four days, so one of us is here . . . It's good that one of us is always here, but that leaves the other seven kids at home with one of us . . . The 9-month baby is the real challenge. We can't just leave her at home, even though the older boys are great, we just don't want to leave them all day long and still expect any kind of schooling to get done (Father 4).*

Fourteen out of the fifteen nurses also commented on the challenges that families face balancing the needs of the family. *“A lot of them have other kids, so the constant battle of worrying about who’s watching them. Do they have childcare lined up? Feeling guilty about not being at home with the children who aren’t here”* (Nurse 8).

### ***Seeing the Child Sick***

Children requiring HSCT often times experience many complications, expected and unexpected, that are hard for the family to face. Although the nurses know what to expect, the families are often shocked to see what the complications really look like in reality, causing significant emotional distress. *“I think just seeing your kid that sick, it gets to you after a while emotionally and psychologically”* (Nurse 7). A mother describes her experience with her child becoming sick and requiring a transfer to the PICU. This mother is not only concerned with what she sees, but what she doesn’t see.

*And she couldn’t breathe. It was just like you could see her really going downhill with the breathing every day . . . She started having pains in her stomach, real bad, like crushing pains like somebody was hitting her in the stomach* (Mother 1).

### ***Work/Financial Obligations***

Most of the parents described their work environment to be very accommodating but balancing work with other obligations was a challenge. Some of the parents had flexible work hours and were able to work from the hospital room, and described their employers as understanding of their situation. Although parents would prefer to take off work, most were not able to do so due to financial obligations.

*My husband just went back to work last Monday, so he was here the whole time. And if the first transplant would have taken, it would have been fine, but he had to go back*

*because he wasn't paid. So we are just using all our donations to pay . . . And that's been the hardest for him that Daddy's not here (Mother 5).*

The nurses seemed to have a different perspective about work and finances for families going through HSCT, and overall thought work and finances were more of a burden. Families were described as facing many challenges having to work and be present at the hospital. Nurses often try to instill in the parents the importance of their presence, but that they recognize that parents have other obligations. Nurses also described that some parents have to stop working to be present for their child.

*I've talked to a multitude of families who one or the other parent is unable to work or unable to keep a job because of the time commitment with the illness that comes with a hem-onc family or a transplant family, specifically (Nurse 10).*

### ***Marital Stress***

A common thread between the parents was how little time they spent together as a couple and as a family. Although very little time was spent together, efforts were made to use technology for communication and strong efforts were made to turn any time spent together into quality time. One mother shared the challenges of not being home with her spouse, who is not the father of the sick child. When family members are not present at the hospital with the sick child, they may not have the perception of the hospital experience.

*She's an adult with a daughter of her own. 'If your daughter was going through something, you'll be there too, so don't keep talking about me, about we don't spend time with each other' . . . so I do give her a little bit more time. I heard her, but at the same time, I had to also tell her to tone it down a little bit because I'm all my daughter has'' (Mother 1).*

Nurses supported the parent perspectives of marital stress, and shared that they have witnessed tension between parents as they sort out their roles during the child's hospitalization. The initial diagnosis and HSCT can be extremely stressful on a marriage, and marriages sometimes end as a result of the stressors surrounding caring for a sick child. *"Sometimes you can pick up on, there's marital problems. You can tell the tension between couples on the phone. One's always raising their voice"* (Nurse 6).

### ***Sleep Deprivation***

Some parents discussed the challenges with sleeping while in the hospital environment with their child, but did appreciate the care taken by the nurses to maintain a quiet and calm environment throughout the night. Other parents talked about the sleeping arrangements and that better amenities would help the parents to sleep more comfortably.

*I'm tired, of course. When I'm here, taking care of my daughter and just being someplace other than home, you don't sleep well anyway. Although some of those nurses are like ninjas. They can sneak in at night and I don't hear them* [laughter] (Mother 4).

Several nurses commented on the lack of sleep that parents experience while caring for their hospitalized child. Unfortunately, the child requires care through the nighttime hours, which can interrupt sleep for the parent. The prolonged hospitalization associated with pediatric HSCT contributes to the chronic lack of sleep that parents experience. *"Lack of sleep. Somebody's coming in your room every hour or more. The pumps are beeping consistently. I feel like they get drained"* (Nurse 7).

### ***Lack of Information***

Keeping families "informed" was a common theme that when not effective, caused significant stress on the families. Because most pediatric transplant centers are affiliated with

academic institutions, there are various levels of providers from attending physicians to residents, so families meet a lot of healthcare professionals. Many programs also have a robust nurse practitioner (NP) team that assists with care and communication with the family. Overall, the parents felt informed, and commented on the daily communication received from the inpatient NP. But there were a few families that thought the communication process could be more organized. One mother compared her inpatient and outpatient experiences, and felt the inpatient communication was not as cohesive.

*I think it's the same attending for a week straight, but sometimes it's different residents and fellows that come in, and sometimes, you cannot get it straight . . . I think of the doctors that we've had since we've been here, I've liked them all. . . but it just feels not as cohesive and connected to your case. I'm not going to say it's a challenge. You figure it out. You work with whomever you've got. But it's just not the same feeling as being part of the clinic team down there because you're always with the same people" (Mother 6).*

The nurses agreed with the parent perspectives that communication with families needs to be more streamlined and organized. There is a large burden placed on the nurses regarding communication with the family concerning important updates. Another nurse commented on the amount of healthcare providers that communicate with the family and how information can be conflicting. The lack of parental knowledge around potential complications was brought up as a concern as well.

*Parents always have questions, and just seeing the nurse is not enough. Just seeing the resident is definitely not enough. They want to see the doctor or that NP who educated them on this or who had them sign the consent for this transplant and who can only really give them answers to the questions that they want because the resident has to then defer*

*to the transplant team” (Nurse 9).*

### ***Transplant-Related Complications***

Transplant complications are a major stressor as it relates to the uncertainty of the course the child will take during the HSCT hospitalization. Half of the parents talked about their child experiencing clinical complications, from primary non-engraftment causing prolonged immunosuppression and hemorrhagic cystitis, to multisystem organ failure in the PICU. One mother was the actual donor to her child, and had to go through the stressful donation process twice, because the first transplant did not engraft. Another parent’s child had a prolonged PICU stay for respiratory and renal failure, and described this experience as a complete loss of control. The nurses also talked about stress on the family when their child is transferred to the PICU. There is a complete change in the care team with new routines, and parents have to adapt to a lot of change when the child is critically ill.

*I did not like the ICU, it feels like I’m signing my child over to death. To me, that’s what it felt like. And I was like, ‘No. We’re going to get of this . . . it’s not time to go yet. You got a whole life to live’. So that’s why I told her to keep fighting. She fought” (Mother 1).*

### ***Prolonged Hospitalization***

The parents did not focus on the length of the hospitalization because there were willing to do whatever it takes to get their child healthy, but the nurses talked about the time commitment as a challenge for families. More complications with the child’s health can prolong the hospitalization, and children are often readmitted after they are discharged home due to ongoing transplant-related complications. The prolonged hospitalization was described as demanding on the family and unpredictable. One nurse stated, *“But I think it’s also just this is their whole world, this little room, for how many weeks, sometimes months” (Nurse 15).*



### ***Single-Room Isolation***

Children who have undergone HSCT are confined to a single patient room until their cells have engrafted, which could take sometimes up to a month. The nurses shared that single room isolation is confining to the family and that the “walls start to close in” after a while. The children possibly need to be confined longer if they don’t engraft and have to be transplanted a second time, or they have a prolonged hospitalization because of transplant-related complications. One mother referred to the patient’s room as her home, and had suggestions of how the team could improve the living conditions.

*We’ve been transplant patients, and they’re confined to a room. I understand you all can’t knock down a whole ward and build rooms with all this different stuff. However, a little small microwave in the room so we don’t have to keep running in and out of the room for stuff like that because some patients do still eat . . . and definitely housekeeping . . . that’s my only gripe. I feel like I clean the room myself. Once again, that’s her home. She can’t come out of that room” (Mother 1).*

### **Coping**

Parents described various methods of coping to the stressors, which included: self-care, emotional outlet, spirituality/religion, normalization, avoidance, and need for information.

### ***Self-Care***

Self-care was described as the parents caring for both their physical and psychological wellbeing. Most of the parents and nurses expressed the need for parents to take periodic breaks while staying with their hospitalized child, even if just a brief time to get coffee, take a walk, or make a phone call. Several of the parents shared their need for exercise and describe how they are staying active, including walking and jogging around the campus.

*I went for a jog this morning. I try to get a little bit of exercise. Normally at home, I go a couple times a week at 5:30 in the morning and play some pick-up basketball with some guys to get a good sweat up. So that hasn't been available. I haven't played basketball for over a month, so I've missed that* (Father 4).

Although most parents did not focus on their physical amenities, a third parent shared that there should be more options available for parents.

*They do a lot of stuff for the kids, but there's not a whole lot of – or easier things for the parents . . . Just you feel like you're stuck in here, and there's not a whole lot for the parents to feel sane . . . I would pay an arm and a leg to go downstairs and get a pedicure, get my hair cut* (Mother 5).

Almost all of the nurses illustrated the need for families to take time for themselves, but that some parents have a hard time leaving their child. One nurse described a parent who neglected her own health to be with her child. That seemed to be a theme with the nurse perspectives. Another nurse encourages parents to take breaks.

*We need to convince some parents that it's okay for them to step away, go home and take a shower in your own house, and do what you need to for yourself, even for a couple hours . . . they come back rejuvenated. They might feel a little guilty for leaving their child, but we provide the reassurance that it's okay to do that for themselves”* (Nurse 3).

### ***Emotional Outlet***

The experience of having a sick child can be extremely stressful and both parents and nurses described the emotional outlet that is needed. One parent shared having to be strong for her daughter while in the hospital setting, but using her alone time for her emotional outlet. This same mother describes how she copes with her daughter being critically ill; while at work, she

smells clothing that her daughter wore or listens to an audio recording of her interacting with her brother to remind her of the child.

*“Do I go home and cry sometimes? All the time after desensitizing myself a little bit when I’m here with her so I can stay strong for her. But when I walk out of here, it would be a different thing in that car. I’ll fight air [laughter]. I scream there like it’s – whatever. But I have to put up something for her”* (Mother 1).

Nurses described the challenges to prepare the parents for how to cope and adapt to their child’s illness. It was shared by one nurse that sometimes families lack coping mechanisms, and are emotional throughout their child’s hospitalization.

*I’ve had some parents in there that have a very hard time coping at all, and they just cry in the room with the kid, and it’s a little distressing for the kid and the other people in the room”* (Nurse 4).

### ***Spirituality/Religion***

Praying and spirituality was a common parental theme as a coping strategy, which can be done anywhere or anytime. Praying was described by one father as a way to cope with a poor prognosis for his three-year-old daughter with neuroblastoma. This father talked positively about having hope and that praying gives him strength. Nurses have witnessed that parents turn to religion, spirituality, and praying as a coping strategy. *“Some parents turn to religion and that’s how they cope best”* (Nurse 14).

*What I will say I do, because he sleeps late, is I’ve started doing a 20-minute morning prayer, and I have found that to be very helpful. That’s probably a coping strategy. I feel much better if I’ve gotten that done before the day starts rolling or anything starts happening. I guess you could liken that to a meditation time, I’m praying* (Mother 6).

## ***Normalization***

The nurses spoke strongly about the need for parents to normalize their situation while the child is hospitalized. Some families try to keep their normal home schedules or activities, like watching the same TV shows or listening to music. When children are hospitalized, they sometimes think they can get away with acting out. Some parents were described as holding their children accountable to the same behaviors that they would if they were not hospitalized.

*They will even try making the child do some homework, I think, just to kind of give them some – to normalize them. I'll hear them say, 'just because you're here doesn't mean you can act like that' . . . they try to make it normal like they would at home (Nurse 6).*

## ***Avoidance***

There were some parents who described that they did not need to cope, or that they would worry about themselves at a later date, after the child was discharged. When the child is doing well (without complications), parents shared they did not need to find ways to cope. One mom described herself as not the priority. *“Being a momma, myself is always last, so that's fine”* (Mother 4). Another second parent shared, *“Overall, we're fine because our son is fine. If my son here doing bad every day, reports from doctors not good, then I would have a reason to cope”* (Mother 2). Nurses recognized that parents sometimes use avoidance as a coping mechanism. One nurse describes that some parents avoid being present for their child as a way of coping.

*Other parents, it's hard to say because I feel like their coping mechanism is, I don't want to use the word avoidance, but they just aren't here and – if that's how you're able to handle this and it's too much, that's understandable too (Nurse 14).*

### ***Need for Information***

Although parents did not describe the need for information as a coping mechanism, the lack of information was a strong theme causing parental stress while the child is hospitalized. Several nurses, however, shared their experiences with how parents cope using knowledge. Allowing parents to participate in care and providing them with information was one way to help parents cope. One type of knowledge described includes information that parents seek out about the patient, including medications and lab results. Parents were also described as turning to online support to stay informed. “

*They turn to different things to feel like they've got control. We've seen families who they feel the need to write down every single medication and time and dose and everything that they received during their stay . . . they want to write down all of the labs (Nurse 3).*

### **Adaptation**

Parents have to adapt both internally and externally to the child's illness, which may include modifying environmental factors or changing their way of thinking. The subthemes that emerged include: work-life-balance, role change, new routine, change in attitude, and sacrifice.

#### ***Work-Life-Balance***

Most of the parents still have to work, even though their child was facing this life-threatening illness. Employers were mostly accommodating for the parents, allowing flexibility in scheduling and working from home. Some nurses were in agreement with the parents that employers are usually accommodating with the parents during the transplant hospitalization, but others described the challenges of being off work, especially after the Family Medical Leave Act (FMLA) time runs out. Most of the children experiencing HSCT require prolonged hospitalizations and time off school lasting much longer than three months, which is challenging

for families to manage. One mother shared: *“My company was good. Even through they’re anti-working from home, they’ve been letting me. Since this all happened, I’ve been able to work from home so that I can get him back and forth”* (Mother 3).

Some parents have challenges with work-life-balance, which affects the child’s psychosocial and physical well being, as described by one nurse. Parents can’t always be present for their child because of other obligations, either family and/or work, which poses problems for especially the younger children. Parents were also described as having to quit their job to be present, which then adds to the financial strain on the family.

*Somebody’s presence is very important for their child. Parents don’t have to stay 24/7, but at least visit your child every day, or every other day, for a couple of hours . . . We have one patient here now . . . the parents are almost never here . . . the child suffers, in my opinion, psychologically, mentally, physically* (Nurse 5).

### ***Role Change***

Parents and nurses both described that roles often time change in the family to adapt to the HSCT experience. Parents have to pick up roles that were different from their normal routines, such as grocery shopping, laundry, and providing respite care for the other parent by staying at the hospital. Role change was described as somewhat challenging by both the parents and nurses, but that the families tend to work together to do what is needed for the child and family.

*Things just need to be done. My wife’s here and laundry needs to be done. Fine. I’ll take it back to the house and just do it . . . We need groceries. Fine. I’ll go out and do it. It’s a couple working together to get through the rest of the life that isn’t related to the cancer . . . but it’s affected by it* (Father 3).

### ***New Routine***

Parents have to rearrange their lives both with the hospitalization and with their child's illness in general. Both parents and nurses talked about the importance of maintaining a routine.

*I think I've been just trying to stay in a schedule where the resident comes in usually between 7:00 and 7:30, and then I get up, take a shower. And if it's a workday, I've been starting work and then trying to get my son into some kind of routine . . . But I think, in my head, I was committed. This is what we're doing, and once I established my schedule, then it's just been fine (Mother 3).*

The nurses commented strongly on how families have to change their routines and schedules, including putting their lives on hold, which is consistent with the parent perspectives. "Some people, they have to kind of rearrange their whole life . . . adjusting their job so they can be here more" (Nurse 4). "They basically have to put their life on hold . . . they have to adapt at basically just not having an outside life at that time" (Nurse 12). Another nurse described the perspective of how the transplant experience affects the whole family. Maintaining a routine was viewed as necessary for adaptation. "The biggest thing that helps families get through such a rocky, shaky point in their life is familiarity and routine" (Nurse 10).

### ***Change in Attitude***

Change in attitude, signified as a different way of thinking when being faced with a life-threatening illness, was the strongest theme that emerged from the parents in how they adapt. All of the parents talked about maintaining a positive attitude as they navigate through this experience. One parent described how she thinks more positively and how she has changed as a mother.

*I have a lot more patience than I ever had. I don't want negativity in my life because it*

*seemed like negativity pull you down . . . I changed everything around me. Everything about me is brand new. I am no longer that person that I was three years ago. I've definitely changed. I've become a better mom, actually. Because now, it's the little things that people take for granted with their kids, I thrive on that"* (Mother 1).

Adapting to social situations was shared by one mother as a challenge. She described how she has changed socially by avoiding situations in which the topic of discussion is her sick child. This mother shared that it can be exhausting talking about her son and preferred social situations, which took her away from this situation.

*I have changed socially . . . it's hard to be somewhere where everybody's like, 'Oh, there's the family whose son is sick' . . . socially, I definitely avoid situations in which I feel that's going to be the topic"* (Mother 6).

Finally, a mother describes how she has to abandon her previous thinking that she does not need help. As a mother of eight children, she is used to doing everything for her children, but now has been forced to adapt and accept outside help so she can be at the hospital with her sick child. This was contrary to the father's view, who was grateful for the help the family received from the church and community.

*I'm not one to usually ask for help . . . I'm always the 'I can do it myself', which is probably where my kids get it from. A little stubborn . . . probably in the very back of my head, it bothers me (to ask for help), but I've learned I have to let it go"* (Mother 4).

### ***Sacrifice***

Several parents shared sacrifices that they have made for their sick child, but that these sacrifices were not a burden on the family, such as missing a birthday or holiday, as described by one father: *"My birthday was in November, and we were here for Thanksgiving. But I'm here*



*with him, so it didn't bother me"* (Father 2). One nurse described sacrifice that parents make as it relates to giving up a job to be present for their child, while another parent shared the overall experience as being a small bump in the road when looking at life as a whole. *"You have to stay positive . . . if our child lives to be 100 years old, then this time of 100 days is just a blip on the radar, nothing more"* (Father 3). Only one mother interviewed was the donor to the child, and she shared that her experience with donation was challenging and painful, but that she was more than happy to sacrifice and go through the procedure. The first transplant did not engraft, so then she had to go through the process again.

*It was a little exciting that I get to be the one to do it. But then when . . . I don't know, it was a little more intense than I thought it was going to be. And then you had to lay there still for six hours, then I was like, 'I've got to do this again [laughter]'"* (Mother 5).

### **Discussion**

Family obligations were described by both the parents and nurses as the most challenging to balance while the child is hospitalized. Social support is needed to help families manage the care of the sick child and the care of others within the family unit (Tillery, Joffe, Mara, Davies, & Pai, 2018). The front-line healthcare team needs to be cognizant of challenges within the family dynamic so that they can tailor the care to meet the needs of the family and not just the child. This may include organizing for a care companion or child life specialist to stay with the child so that the parents can tend to other family members and obligations outside of the hospital setting.

Transplant-related complications emerged as a stressor that families face, whether it is a fear of or an actual experience with known complications, such as organ toxicity, infection, or graft versus host disease. Parental emotional functioning is impaired when the child experiences

clinical transplant complications and prolongs the psychological recovery of the parents to this experience (Terrin et al., 2013) . The PICU experience can be extremely challenging for parents, particularly related to emotional stress and uncertainty (Alzawad, Lewis, Kantrowitz-Gordon, & Howells, 2020). More research is needed to evaluate how to best support families when the child struggles with transplant complications, especially when the child requires a higher level of care in an ICU setting. Although some of the parents shared concerns for financial stability during their child's transplant, they focused more on general worries about taking off work and paying the bills. Kazak et al. (2019) found similar results that families struggle financially during the HSCT experience generally, and that some families have more significant challenges, such as insufficient funds for food and housing. None of the parents interviewed for this study shared significant financial concerns, but some talked more generally about having less money available. It is vital that the multidisciplinary healthcare team assesses and addresses financial concerns and insurance coverage for families prior to HSCT hospitalization.

Parents who expressed that there was a breakdown in communication while the child was hospitalized or didn't feel well informed noted this to be a significant stressor. Internet, online support groups, and involving the parents in the care of the child were found to be interventions that helped parents cope with staying informed. Parental activation, the process of parents taking on the role of co-managing their child, also fosters the parents to stay informed (Pennarola et al, 2012; Pennarola et al., 2015). Another study that explored the experiences of parents who were both the donor and the caregiver to the child found similar results (van Walraven, 2012). Parents overwhelmingly shared that they did not feel well informed of the donation process to their child, which compounded the lack of familiarity within the hospital environment. Kazak et al. (2019) identified that access and communication with an interdisciplinary team is essential and reported

similar findings that some parents expressed they were not supported by their care team. Support and communication from the healthcare team is vital to HSCT experience and helps parent cope during the hospitalization (Lankin et al., in review).

Coping mechanisms are necessary for parents to navigate through the pediatric HSCT experience and help to decrease stress and anxiety that is often times seen with the parents (Cavadini et al., 2019). All of the parents interviewed in this study shared their positive outlook when approaching their child's life-threatening illness and risky treatment. This is consistent with the authors in another study that evaluated the parental perspectives when preparing for their child's HSCT journey and potential outcomes, and found that over half of the parents surveyed did not think their child's health would worsen or the child would die (Ullrich et al., 2016). Although families are educated on the risks and challenges of HSCT, positivity is seen as a coping strategy to avoid the fear and loss of control that comes with the potential complications of HSCT. Ullrich et al. (2016) also found that those families with solid tumors had a worse outlook than those families with a hematologic malignancy, most likely because pediatric solid tumors requiring HSCT carry a worse prognosis than the hematologic cancers. The current study only interviewed the parents from one family in which the child faced HSCT for stage IV neuroblastoma, and although both parents recognized the prognosis, they maintained a positive outlook and were hopeful for a cure. Parents who use hopefulness as a coping strategy also exhibit emotional resilience as they deal with their child's life-threatening illness (Tillery, et al., 2018; Popp, Conway, & Pantaleao, 2015).

Avoidance was recognized as a coping strategy in this study and is described as parents who avoid addressing their own physical and psychosocial needs and those challenges their child faces. The parental use of avoidance as a coping mechanism is associated with the incidence of

greater psychological distress and posttraumatic stress syndrome (Phipps, Dunavant, Lensing, & Rai, 2005; Stoppelbein et al., 2013). Holding back is a social process described by Virtue et al. (2014) in which the parents avoid reaching out to family and friends to express their concerns and fears, leading to more psychological distress. One parent in this study expressed eluding social situations to avoid talking about her sick child, however, support from family and friends is seen as essential for the family experiencing the stressors of pediatric HSCT. Normalization was a coping strategy shared by the nurses, and refers to families trying to maintain some kind of regular schedule and activities that mimics their home environment. Striving for normalcy is a comfort to families and helps the parents maintain stability and hopefulness (Van Schoors et al., 2018).

The pediatric HSCT experience requires that family members adapt to accommodate the needs of the child and life outside of the hospital. Although only one mother shared a lack of presence from the child's father, all of the other parents interviewed were involved in the child's care, and had a strong presence in the hospital setting. Brody and Simmons (2007) explored the views of fathers regarding the effects of their child's cancer diagnosis and learned that all of the fathers were involved in caring for their child, which was not consistent with earlier studies that showed the mother figure took on the role of caring for the child. Almost all of the parents in this current study stated that they are a team with their spouse in adapting to this HSCT experience. Parents described that they switch off at the hospital so that the other parent can take a break, and the responsibilities at home and with the siblings was shared. Parents were noted to make sacrifices for their child in this study, mostly related to time spent at the hospital, lost time with other family members, and missing out on life events. One parent shared her experience as a donor in which she found challenging, but was more than willing to do anything for her child.

This coincides with a study that explored the experiences of parent donors, and found that parents were more than willing to donate, but also the parents felt like they did not have a choice (van Walraven et al., 2012). Family resilience relies on managing stressors, coping, and adapting to the challenges faced throughout the HSCT experience (Van Schoors, Caes, Verhofstadt, Goubert, & Alderfer, 2015).

### **Strengths/Limitations**

This is an innovative and novel study that gathered the perspectives of both the nurses and the parents in describing parental stressors, coping, and adaptation to pediatric HSCT. Interviews were conducted with the participants during the experiences, producing strong results. Triangulation of data from the parents and nurses was used to converge the perspectives and strengthen the credibility of the study. Credibility was also strengthened through a team approach in data analysis. An adaptation from the *Resiliency Model of Family Stress, Adjustment, and Adaptation* was used to guide this study, adding a different perspective to how the healthcare team can understand coping and adaptation strategies of parents during their child's HSCT experience. This study can support further research that concentrates on the individual stressors and interventions to address these stressors, which will support parental coping and adaptation.

One limitation of this study is that the data were collected from a single institution over a twelve-month timeframe in the Midwest of the US. Some of the data gathered may not be entirely reflective of the HSCT experience, but instead, of institutional processes and challenges. More diversity in the sample through a multi-site study, expanding socioeconomic background and ethnicity, would provide an inclusive perspective of the HSCT experience. All non-essential research was held due to two work-force disruptions and COVID-19, leading to fragmented data

collection. The nurses were interviewed at the beginning of the study, and the parents throughout the year. During that year, a nurse practitioner (NP) position was added to the inpatient team, accentuating the communication process between families and the HSCT team. The addition of this new NP position did promote more positive comments from the families in how they communicated with the healthcare team. Further research that focuses on addressing communication with the family throughout the HSCT experience would facilitate knowledge regarding roles within the healthcare team. The nurses were member-checked, but the parents were difficult to follow up with as a result of quarantine practices. The interviewer had no working relationship with the parent participants, but did have a peripheral working relationship with the nurse participants, however only in a clinical support role. The parents were aware that the interviewer was employed at the study site, which may have impacted the parent responses to be more positive. The positivity of the parent responses may have also been a result of the HSCT having a curative goal, and that the child was close to discharge.

### **Practice Implications**

One important role of the healthcare team is to recognize when a family is struggling with the challenges related to the HSCT experience (Phipps et al., 2005; Lindwall et al., 2014; Rodday, Terrin, Leslie, Graham, & Parsons, 2017; Jobe-Shields et al., 2009). Nurses, in particular, are uniquely positioned to assess for parents who are not coping and adapting to the hospitalized child's diagnosis, prognosis, or potential complications, and can advocate for further support interventions. With over 40% of parents reporting unresolved feelings about their child's cancer diagnosis leading to fewer feelings of hopefulness, moving forward into a risky treatment with known complications and mortality can worsen the emotional and psychological distress that parents face (Popp et al., 2015). Transplant complications requiring a higher level

of care in an intensive care setting poses different challenges for the family. The healthcare team needs to better understand how to support families in that situation who are already at a heightened stress level. Support interventions for the family are vital throughout the HSCT experience and may include support from the healthcare team, community, other family members, and from social sources (Lankin et al., in review). Parents reported the support that was most relevant was connecting with other parents and children who went through the HSCT experience (Lankin et al., in review). Hospital-based support groups and family gatherings are activities that nurses often times facilitate as a connection for families who are hospitalized. Nurses can partner with the pediatric stem cell transplant multidisciplinary team to both assess families for emotional distress and stressors that are impairing coping and adaptation mechanisms, and be empowered to participate in support interventions.

### **Conclusion**

This study explored the challenges that parents face during their child's HSCT hospitalization and how parents cope and adapt to this experience. Families struggle most with maintaining their lives outside of the home and with the uncertainties of their child's prognosis as they move through the transplant process. As stressors build, parents need to find ways to cope and adapt to the challenges and rigorous regimen throughout the HSCT experience. If parents don't provide self-care, find emotional outlets, stay well informed, develop new routines and stay positive, coping and adaptation mechanisms can become impaired. During the acute phase of the HSCT experience, families benefit from strong multi-faceted support, including support from their healthcare team, community, family, and social sources (Lankin et al., in review). More interventional research is needed that explores how the healthcare team can support families through this stressful experience during the time the child is hospitalized for

HSCT. Nurses have the knowledge, motivation, and expertise to address the emotional needs of families as they navigate through the pediatric HSCT experience.



### **Acknowledgments**

The research team would like to acknowledge the funding agencies for this study: The DAISY Foundation and the Society of Pediatric Nurses. We would like to thank the members on the Nursing Advisory Committee for their contributions to this research and to James LaBelle, MD, PhD, Associate Professor of Pediatrics, and Director of the Pediatric HSCT program at the University of Chicago Medicine, Comer Children's Hospital. The authors would like to dedicate this paper to the parents and nurses who participated in this research

## References

- Alzawad, Z., Lewis, F.M., Kantrowitz-Gordon, I., & Howells, A.J. (2020). A qualitative study of parents' experiences in the pediatric intensive care unit: Riding a roller coaster. *The Journal of Pediatric Nursing*, 51, 8-14. <https://doi.org/10.1016/j.pedn.2019.11.015>
- Balit, C. R., Horan, R., Dorofaeff, T., Frndova, H., Ing, D., Doyle, J., & Cox, P. (2016). Pediatric hematopoietic stem cell transplant and intensive care: Have things changed? *Pediatric Critical Care Medicine*, 17(3), e109-e116. doi: 10.1097/PCC.0000000000000607
- Barrera, M., Atenafu, E., Doyle, J., Berlin-Romalis, D., & Hancock, K. (2012). Differences in mothers' and fathers' psychological distress after pediatric SCT: A longitudinal study. *Bone Marrow Transplantation*, 47, 934-939. doi:10.1038/bmt.2011.206
- Brody, A.C. & Simmons, L.A. (2007). Family resiliency during childhood cancer: The father's perspective. *Journal of Pediatric Oncology Nursing*, 24(3), 152-165. doi: 10.1177/1043454206298844
- Cavadini, R., Drain, E., Bernaudin, F., D'Autume, C., Giannica, D.I, Giraud, F., Baubet, T., & Taieb, O. (2019). Hematopoietic stem cell transplantation in children with sickle cell anemia: The parents' experience. *Pediatric Transplantation*. <https://doi.org/10.1111/petr.13376>
- Creswell, J., & Miller, D. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39(3), 124-130. doi: 10.1207/s15430421tip3903 2
- D'Auria, J.P., Fitzgerald, T.M., Presler, C.M., & Kasow, K.A. (2015). Through the eyes of young sibling donors: The hematopoietic stem cell donation experience. *Journal of Pediatric Nursing*, 30(3), 447-453. <http://dx.doi.org/10.1016/j.pedn.2014.12.012>

- Dempsey, L., Dowling, M., Larkin, P., & Murphy, K. (2016). Sensitive interviewing in qualitative research. *Research in Nursing and Health*, 39(1), 480-490. doi: 10.1002/nur.21743
- Department of Health and Human Services, National Institutes of Health, National Cancer Institute (2017). Childhood Cancers. Retrieved from [www.cancer.gov](http://www.cancer.gov)
- Donation and Transplantation Statistics (2020). Health Resources and Services Administration, <https://bloodstemcell.hrsa.gov/data/donation-and-transplantation-statistics>
- Drew, D., Goodenough, B., Maurice, L., Foreman, T., & Willis, L. (2005). Parental grieving after a child dies from cancer: Is stress from stem cell transplant a factor? *International Journal of Palliative Nursing*, 11(6), 266-273. <https://doi.org/10.12968/ijpn.2005.11.6.18293>
- Erden, S., Kuskonmaz, B.B., Cetinkaya, D.U., Unal, F., & Ozsungur, B. (2019). Pediatric bone marrow transplantation: Psychopathologic features in recipients along with siblings. *Psycho-Oncology*, 28, 1995-2001. <https://doi.org/10.1002/pan.5179>
- Forinder, U., Posse, E., & Winiarski, J. (2008). Long-term psychosocial support for families of children who have undergone allogeneic stem cell transplant. *Social Work in Health Care*, 47(2), 157-173. <http://dx.doi.org/10.1080/00981380801970335>
- Hill, R. (1949). Families under stress: Adjustment to the crises of war separation and return. Oxford, England: Harper.
- Hinton, D., & Kirk, S. (2017). Living with uncertainty and hope: A qualitative study exploring parents' experiences of living with childhood multiple sclerosis. *Chronic Illness*, 13(2), 88-99. doi: 10.1177/1742395316664959

- HRSA.gov (2020). Donation and Transplantation Statistics. Retrieved from <https://bloodstemcell.hrsa.gov/data/donation-and-transplantation-statistics>
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277-1288. doi: 10.1177/1049732305276687
- Hutt, D., Nehari, M., Munitz-Shenkar, D., Alkalay, Y., Toren, A., & Bieloral, B. (2015). Hematopoietic stem cell donation: Psychological perspectives of pediatric sibling donors and their parents. *Bone Marrow Transplant, 50*(10), 1337-1342. doi: 10.1038/bmt.2015.152
- Ingerski, L. M., Shaw, K., Gray, W. N., & Janicke, D. M. (2010). A pilot study comparing traumatic stress symptoms by child and parent report across pediatric chronic illness groups. *Journal of Developmental and Behavior Pediatrics, 31*(9), 713-719. doi: 10.1097/DBP.0b013e3181f17c52
- Ishida, Y., Honda, Misato, Ozono, S., Okamura, J., Asami, K., Maeda, N., Sakamoto, N., Hiroko, I., Tsuyako, I., Kamibeppu, K., Kakee, N., & Horibe, K. (2010). Late effects and quality of life of childhood cancer survivors: Part 1. Impact of stem cell transplantation. *International Journal of Hematology, 91*(5), 865-876. doi: 10.1007/s12185-010-0584-y
- Jobe-Shields, L., Alderfer, M.A., Barrera, M., Vannatta, K., Currier, J.M., & Phipps, S. (2009). Parental depression and family environment predict distress in children before stem cell transplantation. *Journal of Developmental & Behavioral Pediatrics, 30*(2), 140-146. doi: 10.1097/DBP.0b013e3181976a59
- Kaiser, K. (2009). Protecting respondent confidentiality in qualitative research. *Qualitative Health Research, 19*(11), 1632-1641. doi: 10.1177/1049732309350879

- Kallio, H., Pietila, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: Developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, 72(12), 2954-2965. doi: 10.1111/jan.13031
- Kazak, A.E., Swain, A.M., Pai, A.L.H., Canter, K., Carlson, O., Vega, G., & Joffe, N. (2019). Caregiver perspectives on psychosocial care in pediatric Hematopoietic stem cell transplantation (HCT). *Clinical practice in Pediatric Psychology*. Advance online publication. [Http://dx.doi.org/10.1037/cpp0000278](http://dx.doi.org/10.1037/cpp0000278)
- Kim, H., Sefeik, J. S., & Bradway, C. (2017). Characteristics of qualitative descriptive studies: A systematic review. *Research in Nursing and Health*, 40(1), 23-42. doi: 10.1002/nur.21768
- Knafl, K., & Van Riper, M. (2017). Tips for developing a successful family research proposal. *Journal of Family Nursing*, 23(4), 450-460. doi: 10.1177/1074840717743248
- Koenig, B. A., Back, A. L., & Crawley, L. M. (2003). Qualitative methods in end-of-life research: Recommendations to enhance the protection of human subjects. *Journal of Pain and Symptom Management*, 25(4), S43-S52. doi: 10.1016/S0885-3924(03)00060-5
- Kolins, J., Zbylut, C., McCollom, S., & Aquino, V., (2011). Hematopoietic stem cell transplantation in children. *Critical Care Clinics of North America*, 23(2), 349-376. doi: 10.1016/j.ccell.2011.02.004
- Kronenberger, W. G., Carter, B. D., Edwards, J., Morrow, C., Stewart, J., & Sender, L. (1998). Psychological adjustment of mothers of children undergoing bone marrow transplantation: The role of stress, coping, and family factors. *Children's Health Care*, 27(2), 77-95. [https://doi.org/10.1207/s15326888chc2702\\_1](https://doi.org/10.1207/s15326888chc2702_1)
- Lankin, K., LaFond, C., Hacker, E., Savage, T., Vincent, C., & Hershberger, P. (in review).

Supporting families through the acute phase of the pediatric hematopoietic stem cell transplant experience: Perspectives from parents and nurses.

- Lahaye, M., Aujoulat, I., Vermeylen, C., & Brichard, B. (2017). Long-term effects of haematopoietic stem cell transplantation after pediatric cancer: A qualitative analysis of life experiences and adaptation strategies. *Frontiers in Psychology, 8*, 1-9. doi: 10.2289/fpsyg.2017.00704
- Lin, L., Yeh, C. H., & Mishel, M. H. (2010). Evaluation of a conceptual model based on Mishel's theories of uncertainty in illness in a sample of Taiwanese parents of children with cancer: A cross-sectional questionnaire survey. *International Journal of Nursing Studies, 47*(1), 1510-1524. doi: 10.1016/j.jnurstu.2010.05.009
- Lindwall, J. J., Russell, K., Huang, Q., Zhang, H., Vannatta, K., Barrera, M., Alderfer, M., & Phipps, S. (2014). Adjustment in parents of children undergoing stem cell transplantation. *Biology of Blood and Marrow Transplantation, 20*(4), 543-548. doi: 10.1016/j.bbmt.2014.01.007
- LoBiondo-Wood, G., Williams, L., & McGhee, C. (2004). Liver transplantation in children: Maternal and family stress, coping, and adaptation. *Journal of Specialists in Pediatric Nursing, 9*(2), 59-66. doi: 10.1111/j.1088-145x.2004.00059.x
- MacLeod, K., Whitsett, S., Mash, E., & Pelletier, W. (2003). Pediatric sibling donors of successful and unsuccessful hematopoietic stem cell transplants (HSCT): A qualitative study of their psychosocial experience. *Journal of Pediatric Psychology, 28*(4), 223-231. <https://doi.org/10.1093/jpepsy/jsg010>
- MacQueen, K., McLellan-Lemal, E., Bartholow, K., & Milstein, B. (2008). Team-based codebook development: Structure, process, and agreement. In G. Guest & K. MacQueen

- (Eds.), *Handbook for team-based qualitative research* (pp. 119-135). Lanham, MD: Altamira Press.
- Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal*, 320(7226), 50-52.  
doi: 10.1136/bmj.320.7226.50
- McCubbin, H. I., Cauble, A. E., & Patterson, J. M. (1982). *Family stress, coping and social support*. Springfield, Illinois: Charles C. Thomas Publisher.
- McCubbin, H. I. , & McCubbin, M. A. (1993). Families coping with illness: The resiliency model of family stress, adjustment, and adaptation. In C. B. Danielson, B. Hamel-Bissell, & P. Winstead-Fry (Eds.), *Families, health, & illness: Perspectives on coping and intervention* (21-63). St. Louis, Missouri: Mosby.
- McCubbin, H. I., Thompson, A. I., & McCubbin, M. A. (1996). *Family assessment: Resiliency, coping and adaptation: Inventories for research and practice*. Madison, Wisconsin: University of Wisconsin Publishers.
- McDowell, E., Titman, P., & Davidson, S. (2010). Parents' experiences one year on from their child's hematopoietic stem cell t transplant for primary immunodeficiency. *Journal of Health Psychology*, 15(6), 897-904. doi: 10.1177/1359105309359331
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). New York: Sage Publications, Inc.
- Norberg, A.L., Mellgren, K., Winiarski, J., & Forinder, U. (2014) Relationship between problems related to child late effects and parent burnout after pediatric hematopoietic stem cell transplantation. *Pediatric Transplantation*, 18, 302-309. doi: 10.1111/petr.12228

- Norberg, A.L. & Forinder, U. (2016). Different aspects of psychological ill health in a national sample of Swedish parents after successful paediatric stem cell transplantation. *Pediatric Blood & Cancer*, 63(6), 1065-1069. doi: 10.1002/pbc.25908
- O'Reilly, M., & Parker, N. (2012). Unsatisfactory saturation: A critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research*, 13(2), 190-197. doi: 10.1177/1468794112446106
- Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The Qualitative Report*, 13(4), 695-705. <https://nsuworks.nova.edu/tqr/vol13/iss4/8>
- Packman, W., Gong, K., VanZutphen, K., Shaffer, T., & Crittenden, M. (2004). Psychological adjustment of adolescent siblings of hematopoietic stem cell transplant patients. *Journal of Pediatric Oncology Nursing*, 21(4), 233-248. doi: 10.1177/1043454203262698
- Parsons, S. K., DuHamel, K. N., Ostroff, J., Mayer, D. K., Austin, J., Martini, D. R., Manne, S. (2006). Maternal perspectives on children's health-related quality of life during the first year after pediatric hematopoietic stem cell transplant. *Journal of Pediatric Psychology*, 31(10), 1100-1115. doi: 10.1093/jpepsy/jsj078
- Patton M. Q. (2015). Qualitative designs and data collection. Module 38: Mixed, stratified, and nested purposeful sampling strategies. *Qualitative Research & Evaluation Methods*. 4th ed. Thousand Oaks, CA: Sage Publications, Inc: 305-307.
- Peacock, N., & Paul-Ward, A. (2006). Contemporary tools for managing and analyzing qualitative data. In G. Kielhofner (Ed.), *Research in Occupational Therapy: Methods of Inquiry for Enhancing Practice* (pp. 358-371). Philadelphia, PA: F.A. Davis, Co.
- Pennarola, B. W., Rodday, A. M., Mayer, D. K., Ratichek, S. J., Davies, S. M., Syrjala, K. L., Patel, S., Bingen, K., Kupst, M.J., Schwartz, L., Guinan, E.C., Hibbard, J.H., & Parsons,



- S. K. (2012). Factors associated with parental activation in pediatric hematopoietic stem cell transplant. *Medical Care Research and Review*, 69(2), 194-214. doi: 10.1177/1077558711431460
- Pennarola, B.W., Rodday, A.M., Bingen, K., Schwartz, L.A., Patel, S.K., Syrjala, K.L., Mayer, D.K., Ratichek, S.J., Cuinan, E.C., Kupst, M.J., Hibbard, J.H., & Parsons, S.K. (2015). Changing factors associated with parent activation after pediatric hematopoietic stem cell transplant. *Supportive Care in Cancer*, 23, 1997-2006. doi: 10.1007/s00520-014-2544-1
- Pentz, R.D., Alderfer, M.A., Pelletier, W., Stegenga, K., Haight, A.E., Hendershot, K.A., Dixon, M., Fairclough, D., & Hinds, P. (2014). Unmet needs of siblings of pediatric stem cell transplant recipients. *Pediatrics*, 133(5), 1156-1162. doi: <https://doi.org/10.1542/peds.2013-3067>
- Phipps, S., Dunavant, M., Lensing, S., & Rai, S. (2005). Psychosocial predictors of distress in parents of children undergoing stem cell or bone marrow transplantation. *Journal of Pediatric Psychology*, 30(2), 139-153. doi:10.1093/jpepsy/jsi002
- Popp, J.M., Conway, M., & Pantaleao, A. (2015). Parents' experience with their child's cancer diagnosis: Do hopefulness, family functioning, and perceptions of care matter? *Journal of Pediatric Oncology Nursing*, (32-4), 253-260. doi: 10.1177/1043454214563404
- Riva, R., Forinder, U., Arvidson, J., Mellgren, K., Toporski, J., Winiarski, J., & Norberg, A. (2014). Patterns of psychological responses in parents of children that underwent stem cell transplantation. *Psycho-Oncology*, 23, 1307-1313. doi:10.1002/pon.3567
- Rodday, A.M., Terrin, N., Leslie, L.K., Graham, R.J., & Parsons, S.K. (2017). Understanding the relationship between child health-related quality of life and parent emotional

- functioning in pediatric hematopoietic stem cell transplant. *Journal of Pediatric Psychology*, 42(7), 804-814. doi:10.1093/jpepsy/jsx047
- Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing and Health*, 33, 77-84. doi: 10.1002/nur.20362
- Santacroce, S. J. (2003). Parental uncertainty and posttraumatic stress in serious childhood illness. *Journal of Nursing Scholarship*, 35(1), 45-51. doi: 10.1111/j.1547-5069.2003.00045.x
- Seidman, I. (2013). *Interviewing as qualitative research: A guide for researchers in education & the social sciences* (4<sup>th</sup> Ed.). New York, NY: Teachers College Press.
- Switzer, G.E., Bruce, J., Kiefer, D.M., Kobusingye, H., Drexler, R., Besser, R.M., Confer, D.L., Horowitz, M.M., King, R.J., Shaw, B.E., van Walraven, S.M., Wiener, L., Packman, W., Varni, J.W., Pulsipher, M.A. (2016). Health-related quality of life among pediatric hematopoietic stem cell donors. *Journal of Pediatrics*, 178, 164-170. doi: 10.1016/j.jpeds.2016.07.009
- Tanzi, E. M. (2011). Health-related quality of life of hematopoietic stem cell transplant childhood survivors: State of the science. *Journal of Pediatric Oncology Nursing*, 28(4), 191-202. doi: 10.1177/1043454211408100
- Terrin, N., Rodday, A., Tighiouart, H., Chang, G., & Parsons, S. (2013). Parental emotional functioning declines with occurrence of clinical complications in pediatric hematopoietic stem cell transplant. *Support Care in Cancer*, 21, 687-695. doi: 10.1007/s00520-012-1566-9
- Tillery, R., Joffe, N.E., Mara, C.A., Davies, S.M., & Pai, A.L. (2018). Longitudinal examination of family efficacy following pediatric stem cell transplant. *Psycho-Oncology*, 27(8),

1915-1921. doi: 10.1002/pon.4741

Ulin, P., Robinson, E., & Tolley, E. (2005). *Qualitative methods in public health: A field guide for applied research*. San Francisco, CA: Jossey-Bass.

Ullrich, C.K., Rodday, A.M., Bingen, K., Kupst, M.J., Patel, S.K., Syrjala, K.L., Harris, L.L., Recklitis, C.J., Schwartz, L., Davies, S., Guinan, E.C., Chang, G., Wolfe, J., & Parsons, S.K. (2016). Parent outlook: How parents view the road ahead as they embark on hematopoietic stem cell transplantation for their child. *Biology of Blood and Marrow Transplant*, 22(1), 104-111. doi: 10.1016/j.bbmt.2015.08.040

Van Schoors, M., Mol, J.D., Morren, H., Verhofstadt, L.L., Goubert, L., & Van Parys, H. (2018). Parents' perspectives of changes within the family functioning after a pediatric cancer diagnosis: A multi family member interview analysis. *Qualitative Health Research*, 28(8), 1229-1241. doi: 10.1177/1049732317753587

Van Schoors, M., Caes, L., Verhofstadt, L.L., Goubert, L., & Alderfer, M.A. (2015). Systematic review: Family resilience after pediatric cancer diagnosis. *Journal of Pediatric Psychology*, 40(9), 856-868. doi: 10.1093/jpepsy/jsv055

van Walraven, S.M., Ball, L.M., Koopman, H.M., Switzer, G.E, Ropes-de Jong, C.M.H., de Jong, A., Bredius, R.G.M., & Egeler, R.M. (2012). Managing a dual role – Experiences and coping strategies of parents donating haploidentical G-CSF mobilized peripheral blood stem cell to their children. *Psycho-Oncology*, 21, 168-175. doi: 10.1002/pon.1885

Virtue, S. M, Manne, S., Mee, L., Bartell, A., Sands, S., Ohman-Strickland, P., & Gajda, T. M. (2014b). The role of social and cognitive processes in the relationship between fear network and psychological distress among parents of children undergoing hematopoietic

- stem cell transplantation. *Journal of Clinical Psychology in Medical Settings*, 21, 223-233. doi: 10.1007/s10880-014-9403-6
- Weber, J. G. (2011). Individual and family stress and crises. Thousand Oaks, California: SAGE Publications, Inc.
- White, T., Hendershot, K. A., Dixon, M., Pelletier, W., Haight, A., Stegenga, K., Alderfer, M.A., Cox, L., Switchenko, J.M., Hinds, P., & Pentz, R. (2017). Family strategies to support siblings of pediatric hematopoietic stem cell transplant patients. *Pediatrics*, 139(2). doi: 10.1542/peds.2016-1057.
- Wiener, L.S., Steffen-Smith, E., Battles, H.B., Wayne, A., Love, C.P., & Fry, T. (2008). Sibling stem cell donor experiences at a single institution. *Psycho-Oncology*, 17(3), 304-307. doi: 10.1002/pon.1222
- Wilkins, K., & Woodgate, R. (2007a). An interruption in family life: Siblings' lived experience as they transition through the pediatric bone marrow transplant trajectory. *Oncology Nursing Forum*, 34(2), 28-35. doi: 10.1188/07.ONF.E28-E35
- Wilkins, K., & Woodgate, R. (2007b). Supporting siblings through the pediatric bone marrow transplant trajectory: Perspectives of siblings of bone marrow transplant recipients. *Cancer Nursing*, 20(5), 29-34. doi: 10.1097/01.NCC.0000290811.06948.2c

Table 6

*Stressors, Coping, and Adaptation Inclusion Criteria: Parent and Nurse*

Inclusion Criteria	Exclusion Criteria
Parent	
Parent/caregiver is English speaking and $\geq$ 18 years of age	Parent who requires a translator to communicate and/or is <18 years of age
Child is hospitalized for a HSCT – can be subsequent transplants if they are enrolled in a protocol that requires more than one transplant	Child is readmitted for complications after discharge home for HSCT
Primary parent of the child – actively involved with the care of the child in the hospital setting	Parent not present during the hospitalization for the child’s HSCT
Autologous or allogeneic transplant for any disease process – malignant or non-malignant (efforts will be made to recruit both)	Child is critically ill in the PICU setting or deemed terminal
Parent willing to participate in one interview at one time point towards the end of the hospitalization time frame – optional follow-up interview at least 24 hours after the first interview while the child is still hospitalized	
Patient has not died or is not imminently dying – admission to the PICU will not be excluded	
Nurse	
Pediatric oncology/HSCT nurse who is off orientation	Pediatric oncology/HSCT nurse who is currently in orientation to the inpatient care unit
Pediatric oncology/HSCT nurse who has worked at the study institution for 6 months	Pediatric oncology/HSCT nurse who has not worked at the study institution for 6 months
Pediatric oncology/HSCT nurse who cared for a HSCT patient within the last 2 months	Pediatric Oncology/HSCT nurse has not cared for a HSCT patient in the past 2 months
Willing to participate in the study and provide one interview at one time point	Float nurses and registry nurses not based on the in-patient pediatric oncology unit
Nurses who work any shift – including dayshift, nightshift, or rotating shift – efforts will be made to recruit different shifts to be represented	

Table 7

*Stressors, Coping, and Adaptation Interview Guide: Example Questions*

<i>Parent Interview Questions (First Interview)</i>
<p>6. <b>Introductory Questions:</b></p> <ul style="list-style-type: none"> <li>Describe your child's disease, when he/she was diagnosed, and what that was like?</li> <li>Describe the experience of learning that your child would require a HSCT?</li> <li>How did you prepare for your child's transplant? How did the healthcare team prepare you for this journey?</li> </ul>
7. <b>(Stressors)</b> What have been the biggest challenges during your child's hospitalization for transplant?
8. <b>(Stressors)</b> Have there been other stressors that have occurred besides your child's illness?
9. <b>(Coping)</b> Have you been able to take care of your own needs during your child's hospitalization? (What kinds of things do you do to take care of yourself during this hospitalization that helps you care for your child?)
10. <b>(Adaptation)</b> What have you needed to change in your life after your child became ill and when your child was hospitalized for the transplant?
<i>Parent Interview Questions (Second Interview)</i>
3. Is there anything that you have thought about since our first meeting that you wanted to discuss or clarify?
4. Do you have additional thoughts that you want to add about your hospitalization experience?
<i>Nurse Interview Questions</i>
8. <b>(Stressors)</b> What are the biggest challenges or stressors for the families during the transplant hospitalization?
9. <b>(Stressors)</b> Have you seen other stressors for the family arise during the hospitalization for transplant?
10. What challenges do you face when caring for these patients?
11. <b>(Coping)</b> What have you seen families do to cope with their child's illness during the hospitalization for HSCT?
12. <b>(Adaptation)</b> What changes have the families needed to make during their hospitalization for HSCT?

Table 8

*Stressors, Coping, and Adaptation Parent Demographic Data: N=10 (6 Families)*

<b>Variable</b>	<b>Count (%)</b>
Gender: Female	6(60%)
Male	4(40%)
Race/Ethnicity	
White/Caucasian	7(70%)
Black/African American	3(30%)
Education	
High School Diploma	2 (20%)
Trade School	2 (20%)
Associates Degree	2 (20%)
Baccalaureate Degree	3 (30%)
Masters Degree	1 (10%)
Employment Status	
Full-time	6 (60%)
Self-Employed	2 (20%)
Unemployed	1 (10%)
Other	1(10%)
Married Status	
Married	10 (100%)
Type of Transplant	
Autologous	3(50%)
Allogeneic	
Sibling Donor	1 (17%)
Parent Donor/Haplo	1 (17%)
Matched Unrelated Cord	1 (17%)
Disease	
Hodgkin's Lymphoma (Auto)	2 (40%)
Congenital Neutropenia (Allo)	1 (17%)
Neuroblastoma (Auto)	1 (17%)
Fanconi's Anemia (Allo)	1 (17%)
MDS - Post ALL (Allo)	1 (17%)
Family Role	
Stay with child	2 (20%)
Work	1 (10%)
Both (stay/work)	7 (70%)
<b>Variable</b>	<b>Mean(yrs)</b> <b>Range(yrs)</b>
Age (parent)	41.9 30 to 56
Age (child)	11.2 3 to 19

Table 9

*Stressors, Coping, and Adaptation Nurse Demographic Data: N=15*

Variable	Count (%)	
Gender: Female	15(100%)	
Race/Ethnicity		
White/Caucasian	9(60%)	
Asian	2(13%)	
Black/African American	2(13%)	
Latino/Hispanic	1(7%)	
Other	1(7%)	
Highest Nursing Education		
Baccalaureate (BSN)	15 (100%)	
Masters (MSN)	3(20%)	
Shift		
Dayshift	8(53%)	
Nightshift	7(47%)	
Variable	Mean(yrs)	Range (yrs)
Age	37	26 to 62
Years as a Nurse	13.1	3 to 37
Years as an Oncology Nurse	9.7	1.5 to 28



Table 10

*Sample Quotations: Stressors, Coping, and Adaptation*

<b>Theme</b>	<b>Subtheme</b>	<b>Quote</b>
<b><i>Stressors</i></b>	<i>Family Obligations</i>	<p>“I think what goes on here creates a stress on our family, probably most noticeably what goes on with our daughter – she’s the younger one – because it’s out of her wheelhouse of control. So she’s kind of at the mercy of whatever family member is kind of taking things over for us” (Mother 6).</p> <p>“There’s a lot of running around, back and forth. And we leave my daughter home a lot . . . sometimes, my son will be home or she might go to her grandparents, but she stays home a lot . . . and she says she enjoys it [laughter]” (Father 6).</p>
	<i>Seeing the Sick Child</i>	<p>“So things are a lot different in real life than they are on paper. To read on paper that they might end up with mucositis, and then to see their child throwing up the lining of their stomach . . . the reality of everything is very harsh” (Nurse 3).</p> <p>“What if she gave up underneath that life support system, and then all her organs start failing? That’s what I was thinking that it was all about because every time I ever heard of somebody on life support, that’s what happened to them (Mother 1).</p>
	<i>Work/Financial Obligations</i>	<p>“Our jobs have been great . . . so luckily, money hasn’t been an issue because we’ve been getting paid, and our insurance has been wonderful, we haven’t had to work about anything like that” (Mother 3). “We do the best we can trying to make it. We got a house, which my mother-in-law is the owner of the house, so it kind of helps a little bit, but the bills, water, gas, lights, all that stuff just keep - - they don’t stop. They don’t care about what you’re going through” (Father 2).</p> <p>“I think just being here 24/7 . . . Both parents work, so I just try to tell them if you have someone that could stay here with them, maybe try to work as much as you can, especially if you carry the insurance. Because if they do get sick, you want to be here” (Nurse 11).</p>
	<i>Marital Stress</i>	<p>“I guess for the last month, I’ve probably seen my wife an hour and a half to two hours a week, so that’s kind of tough, but we take advantage of technology. We try to do a Facetime every night with the whole family and just try to stay a little bit connected” (Father 4).</p>

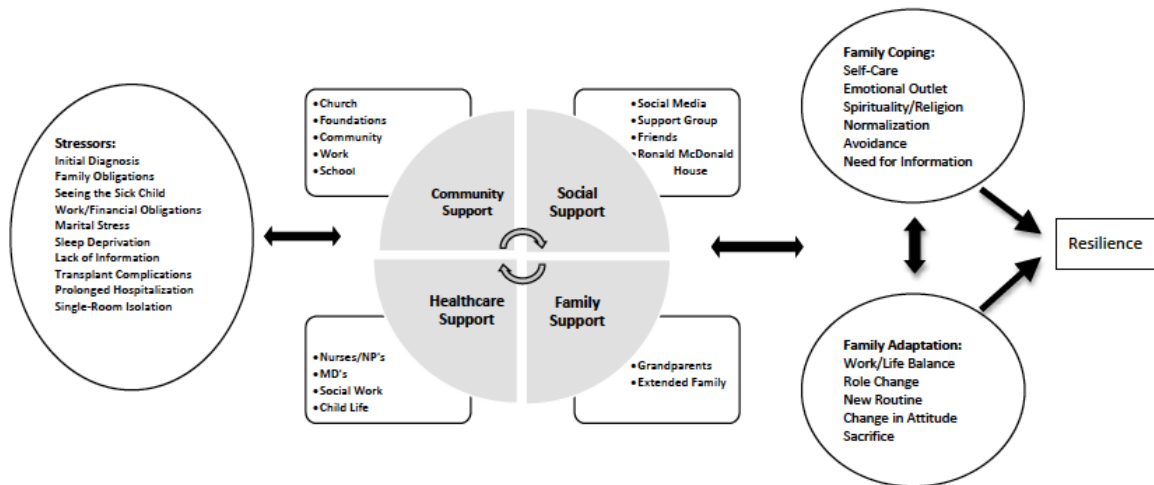
		<p>“A transplant can be very stressful in a relationship. Having a child with cancer can be very stressful in your relationship. For a lot of people, just the diagnosis alone can be enough to ruin a marriage” (Nurse 8).</p>
	<i>Sleep Deprivation</i>	<p>“When I stay here, I’ll sleep on the little couch. I don’t sleep well in here, but it’s all right [laughter]” (Father 6).</p> <p>“I feel like parents, they don’t sleep because they can’t. This is not a sleep-inducing environment, which is fine if you’re only here for 24 hours. But if you’re here for three months, when are you supposed to sleep?” (Nurse 8).</p>
	<i>Lack of Information</i>	<p>“I love Madeline too! . . . whatever they need to keep that position, that’s great because she’s so knowledgeable. And she’ll always come here so you feel like you’re kind of getting two times the information because I’ll talk to her first, and then the doctors will come and she comes back” (Mother 5).</p> <p>“Lack of information or conflicting information . . . from various providers, whether it’s nurses, physicians, nurse practitioners, dieticians . . . I think we don’t do a good job of explaining to them the potential that they could be transferred to the ICU for any number of reasons” (Nurse 8).</p>
	<i>Transplant-Related Complications</i>	<p>“The first one didn’t take . . . with this Fanconi anemia, they’re harder to engraft . . . they were trying to be maybe not so rough with the chemo because the chemo’s what hurts these kids with Fanconi. And it wasn’t strong. I don’t think it killed off his cells” (Mother 5).</p> <p>“A lot of stressors I find is when the child starts to get sick . . . a kid who’s visually struggling to breathe or they’re having a reaction to a medication . . . If they need any more respiratory support, we have to go to the PICU . . . brand new unit, brand new routine, brand new set of nurses who don’t know those little quirks . . . the biggest stressor is any change in routine” (Nurse 10).</p>
	<i>Prolonged Hospitalization</i>	<p>“I know we’ve had a couple that have been here for maybe up to four months, just depending on the complications post-transplant, or they get discharged and are frequently coming back” (Nurse 12).</p>
	<i>Single-Room Isolation</i>	<p>“But for the parents that are stuck here and stay in the room and they feel like the walls start to close in on them after a while, once they’re here for so long” (Nurse 7).</p>
<b>Coping</b>	<i>Self-Care</i>	<p>“I’m the only one who’s gotten away. She (mom) won’t leave. It’s a mom thing. I understand that. She’s got a couple of her friends who are coming down, and they’ll go sit in Starbucks for an hour which will be good for her” (Father</p>

		<p>3).</p> <p>“Mom has to take care of herself. Mom has to attend the doctor’s appointment because endocrinology appointments are tough to come by, and if she not getting her insulin, she’s not taking care of herself. She needs to be available for her child, but she needs to be healthy as well” (Nurse 8).</p>
	<i>Emotional Outlet</i>	<p>“I came back and they had everything in her. That’s the worst. And I couldn’t hear her voice. So I went through a spell where I had this recording of her when she was about six years old, and she was with her brother . . . I couldn’t get that out of my head. Then I would take socks of hers home when I take it off her foot just smell her when I’m at work” (Mother 1).</p> <p>“But it’s hard because, how do we prepare them to learn how to cope? How do we guide them through the stages of grief, or give them appropriate ways to cope? No one wants to be handed that because like, ‘Why am I going to be coping soon? Why are you giving me this packet on coping?’ But you never know what they’re going to be upset about and when they’re going to need it” (Nurse 4).</p>
	<i>Spirituality/Religion</i>	<p>“Praying a lot, more even since this. Really, we’ve lived a very charmed life – eight babies, no miscarriages, no real sickness in our family. Healthy family. Enjoyed traveling. Just, I mean, super blessed . . . so this is a pretty big blow, the cancer diagnosis and the bad prognosis that chances are she won’t be alive in five years” (Father 4).</p>
	<i>Normalization</i>	<p>“I also think just taking themselves out of the situation for a day or two, living their normal lives, hanging out with their other kids” (Nurse 15).</p> <p>“Some try to make it normalized here by watching their normal television channels or listen to music and things of that nature” (Nurse 2).</p>
	<i>Avoidance</i>	<p>“It’s not that I’m not able to (cope). I’m sure I could, but I think my mindset is, ‘This is where I need to be’. And so going back to being prepared for what this would look like, I think I was very much prepared for what this would entail and the time we would need to be here. And so I feel it’s gone faster than I’ve expected. It’s gone better than I’ve expected . . . I’m focused, and it’s a job. And maybe when it’s over, I’ll go get a manicure or a pedicure [laughter], but until then, I think I’m all right” (Mother 6).</p>
	<i>Need for Information</i>	<p>“Let them participate in whatever you need to do and always inform them” (Nurse 5).</p>

		<p>“Sometimes they talk to other families . . . going online, finding more information that they could bring up to the docs” (Nurse 11).</p>
<b>Adaptation</b>	<i>Work-Life-Balance</i>	<p>“I feel like we had the perfect jobs to incorporate what’s going on right now. Perfect time, perfect space, perfect everything. I’m just glad it’s still just two parents, so more support” (Mother 2).</p> <p>“The majority of the families that I have interacted with, their employers have been as understanding as they possibly can be. But, unfortunately, in the American system, a lot of these companies’ hands are tied. They don’t have internal policy about parents taking extended leave to care for a sick child beyond the federally mandated FMLA. I do feel most of the companies try and be accommodating” (Nurse 8)</p>
	<i>Role Change</i>	<p>“They have to have a different role. You can be mommy to four, and suddenly, you have to be super mommy to one. And I feel like that’s a huge change” (Nurse 15).</p>
	<i>New Routine</i>	<p>“I honestly thank God that he was born with this, but we didn’t find out until now, and then it was transplant time . . . I quit going to the gym. I quit working. I quit going out. We don’t do date nights. I mean, life has just completely been at a standstill. So I always am wondering, if we would have found this out from birth, would I have always been like that and just waiting for a transplant to happen?” (Mother 5).</p> <p>“There’s a lot of things I feel like they have to change . . .you can’t take one kid to McDonald’s because the other kid that just had the transplant can’t get McDonald’s. That’s not very fair. So just basic silly things that you wouldn’t think are a big deal, could be to a five-year-old” (Nurse 7).</p>
	<i>Change in Attitude</i>	<p>Mostly, just the mental outlook . . . maybe I was just a little more passionate about some of the things going on in the world. Now, it’s like, more entertainment value. I’ve just learned how to take a couple steps back” (Father 3).</p>
	<i>Sacrifice</i>	<p>“Usually, it’s the parent who has the job that provides the insurance that winds up staying at work, and the one who can make the sacrifice, who doesn’t carry the benefits, is the one who stays at the bedside . . . most parents cannot work when the patient is here, which is a huge imposition” (Nurse 8)</p>

Figure 2

*Family Support, Coping, and Adaptation Conceptual Model of Resilience: Pediatric HSCT*



*Note.* The design, measures, analysis, and summation of this study were guided by an adaptation from the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin et al., 1996; McCubbin & McCubbin, 1993; McCubbin, Gauble, & Patterson, 1982). Family stressors, family support, coping, and adaptation progress on a continuum throughout the pediatric HSCT experience. Managing stressors with adequate family support foster coping and adapting, leading to family resiliency.

## APPENDIX A

AURA



THE UNIVERSITY OF  
CHICAGO



BSD IRB

The University of Chicago Biological Sciences Division/University of  
Chicago Medical Center

5841 S. Maryland Ave., MC7132, I-625, Chicago, IL 60637

FWA00005565

### Notification of Expedited Approval

**Date of Letter:** 5/16/2019

**Protocol** [IRB19-0308](#)  
**Number/Submission**  
**Link:**

**Type of** New Study  
**Submission:**

**Status:** Approved - Continuing Review Not Required

**Principal** Cynthia Lafond  
**Investigator:**

**Protocol Title:** Supporting Families Through the Acute Phase of the Pediatric Hematopoietic  
Stem Cell Transplant (HSCT) Experience: Perspectives from Parents and Nurses

**Risk Level:** Minimal Risk

**Consent Type:** Informed Consent

Written Consent Form: Signed consent will be sought from the subject or the  
subject's legally authorized representative

**Authorization Type:** Signed HIPAA authorization (combined with consent form)  
Request for waiver of HIPAA authorization

**Vulnerable** None  
**Populations:**

**Funding:** Internally Funded

**Protocol Version:** Research Proposal 2019-10.docx

**Approval Date:** 5/16/2019

The above-referenced study was approved by the IRB. If the study is conducted as approved by the IRB, a continuing review is not required to be submitted to the IRB. However, if changes are made to the approved study, please submit an amendment to the IRB. If an unanticipated problem occurs, please notify the IRB.

## APPENDIX A (continued)

The IRB may require that an update on your current study status be submitted in the future. You will be notified when this report should be submitted.

When all study activities are complete or the study is no longer active, please submit a termination request to formally close it. Termination requests are submitted in AURA by selecting "Termination by PI".

Stamped approved documents associated with this study can be found in the study workspace, by following the Submission Link above.

If you need assistance, please contact the IRB office.

Please refer to your IRB's current policy and procedure manual available at:

<http://bsdirb.bsd.uchicago.edu>.

## APPENDIX B



### Clinical Trials Review Committee

Hedy Kindler MD, Chairman  
Russell Szmulewitz MD, Vice-Chairman

5841 S. Maryland Avenue, MC 1140  
Chicago, Illinois 60637  
Phone: (773) 702-6180  
Fax: (773) 702-9311

### CERTIFICATION LETTER

Principal Investigator: **LaFond, Cynthia**

CTRC Number: **19-011** IRB Number: **To Be Added**

Protocol Title: **Supporting Families Through the Acute Phase of the Pediatric Hematopoietic Stem Cell Transplant (HSCT) Experience: Perspectives from Parents and Nurses**

Initial Meeting Date: **1/10/2019**

---

**STATUS: Approved**

CTRC guidelines require PI to respond within 60 days of signature date; failure to do so will result in the withdrawal of the application. The application will need to be resubmitted for full committee review.

Protocol Comments:

None

Statistical Comments:

None

Human Imaging Research Office (HIRO) Comments:

None

Other Comments:

None

Protocol Risk Level: **Minimal**

Based on the UCCCC NCI approved Data and Safety Monitoring Plan, the level of risk for this protocol has been determined to be: Minimal-There is no requirement for weekly safety monitoring conference or completion of Data and Safety Monitoring Minutes. This study will be audited every 3 years.

**The research protocol and/or consent form(s) described above has been reviewed by the UCCCC CTRC with the results as indicated above effective on the date of signature below.**

  
\_\_\_\_\_  
Signature of Chair

  
\_\_\_\_\_  
Date

Federal regulations require that any severe adverse drug reaction or adverse occurrence to subjects during the conduct of this research be reported to the UCCCC Cancer Clinical Trials Office (CCTO).



## APPENDIX C



February 6, 2019

Dear Ms. Lankin,

Your proposal was reviewed at the University of Chicago Medicine Nursing Research Council meeting on February 3, 2019. We are pleased to inform you that your proposal *Supporting Families Through the Acute Phase of the Pediatric Hematopoietic Stem Cell Transplant (HSCT) Experience: Perspectives from Parents and* has been accepted. After careful review, your revisions satisfactorily address protection of nurses as research subjects required for the committee's approval. We appreciate your careful consideration of our recommendations.

We have some suggestions for your consideration. These suggestions are not required.

- I. We recommend you use the [nursing.research@uchospitals.edu](mailto:nursing.research@uchospitals.edu) email address to communicate recruitment materials to nursing staff, as this email address does not come from a specific individual. We are happy to assist you. The unit manager can share a unit distribution list with us.
- II. Clarify in the protocol that family members who are not legal guardians of the child/patient will not participate in the research if the child's legal guardian(s) refuse participation.
- III. Recruitment flyers for parents/family would benefit from the review of our health literacy program to ensure language is easily understood. Additionally, stating participation will "go through 2019" may be confusing to parents that they will be participating in the research for a year. Please consider revision.

If you have not yet done so, you may submit your proposal to the University of Chicago Institutional Review Board (IRB). Please visit <http://aura.uchicago.edu/> to complete the IRB submission. Please be sure to indicate that Nursing Research Committee review is required for your proposal in AURA under section 2.1 Research Categories "Required Additional Reviews." This will allow us to communicate approval of your study to the IRB. If you have questions or would like further assistance, please contact the Nursing Research Council co-chairs. We wish you continued success in your research endeavors.

Thank you,

*The University of Chicago Nursing Research Council*

Co-chairs:

Cynthia LaFond PhD, RN, CCRN-K  
Edgardo Javelons, PhDc, CCRN  
Lindsay Schenck Basto, MSN, RN

## APPENDIX D

### UNIVERSITY OF CHICAGO MEDICAL CENTER Clinical Care Center Review Form

INSTRUCTION: Review by Nurse Manager(s)/Director(s) who have management and leadership responsibilities for areas involved in the study are required to document their review and to give permission to conduct the research in their respective area(s). Duplicate this form if multiple individuals are needed to approve.

TITLE OF STUDY: Supporting Families Through Pediatric (HSCT) Experience: Perspectives from Parents/Nurses

APPLICANT/INVESTIGATOR: Kelly Lankin, MS, RN, CCRN-K

I. Clinical Feasibility

Can the study be feasibly conducted on your unit? ☒ Yes ☐ No  
If no, please comment:

II. Nursing Participation

Will the needed personnel be available during prospected data collection time? ☒ Yes ☐ No  
If no, please comment.

III. Additional Comments/Remarks

☒ I have read the application or proposal, understood the operational techniques involved and approve the conduct of this study on my unit.

☐ I disapprove the conduct of this study on my unit.

Tamia Walker  
Print Name of Care Center Leader

Walker  
Signature of Care Center Leader

1/18/19  
Date

## APPENDIX E

### IRB Authorization Agreement

Name of Institution or Organization Providing IRB Review (Institution A): University of Chicago  
IRB Registration#: IRB Committee A: IRB00000331; IRB Committee B: IRB00000735; IRB Committee C: IRB00002169  
Federal wide Assurance (FWA)#, if any: FWA00005565

Name of Institution Relying on the Designated IRB (Institution B): University of Illinois at Chicago  
OHRP Federal wide Assurance (FWA) #: FWA #: 00000083

The Officials signing below agree that Institution B may rely on the designated IRB for review and continuing oversight of its human subject research described below: (choose one)

☐ This agreement applies to all human subject research covered by Institution B's FWA.

☒ This agreement is limited to the following specific protocol(s):

Name of Research Project: Supporting Families Through the Acute Phase of the Pediatric Hematopoietic Stem Cell Transplant (HSCT) Experience: Perspectives from Parents and Nurses  
Name of University of Chicago Principal Investigator: Cynthia LaFond, PhD, RN, CCRN-K  
UC IRB Study Number: IRB 19-0308  
Sponsor or Funding Agency: N/A  
Award Number, if any:

☐ Other (describe):

The Reviewing Institution's IRB agrees to the following in regard to the above listed research protocol or activities:

- I. Provide initial and continuing review in accordance with 45 CFR 46 and its FWA.
- II. Arrange for prompt reporting to the Relying Institution's IRB of any of the following, as defined and determined by the Reviewing Institution's IRB:
  - a. Any unanticipated events or problems involving risks to subjects or others.
  - b. Any serious or continuing non-compliance.

## APPENDIX E (continued)

- c. Any suspension or termination of IRB approval.
- III. Comply with all applicable Federal, State and Local laws and regulations.
- IV. IRB meeting minutes will be made available to the Relying Institution's IRB upon request.
- V. Copy the Relying Institution on all correspondence to regulatory agencies if reporting of an event is required.

The Relying Institution remains responsible for the following:

- I. Ensuring research activities at its site are in compliance with the IRB's determinations and with the terms of its OHRP-approved Assurance.
- II. Adhering to its institutional conflict of interest policies and procedures and providing the Reviewing Institution with any applicable COI management plan related to the study.
- III. Ensuring principal investigators and other research personnel involved in the research are appropriately qualified and meet its institutional standards for eligibility to conduct research, including, but is not limited to, having the required professional staff appointments, credentialing, insurance coverage, and background checks for their assigned role in the research and training in the protection of human subjects.

This document must be kept on file at both institutions and provided to OHRP upon request. This agreement will become effective upon the date of the last signature by the institutional officials below and will remain in effect until such time that either institution provides 30 days written notice of termination to the other institution.

Signature of Signatory Official (Institution A):

Print Full Name: Michael R. Ludwig

Institutional Title: Associate Vice-President for Research, Director University Research Administration

Date: 6/2/19

Signature of Signatory Official (Institution B):

Print Full Name: Joanna Groden, PhD

Institutional Title: Vice Chancellor for Research, University of Illinois at Chicago

Date: 4/4/19

## VITA

Kelly Lankin, MS, RN, CCRN-K

### Educational Preparation:

---

2014 – Present	Doctor of Philosophy in Nursing, projected graduation December 2020 PhD Candidate The University of Illinois, Chicago (UIC), Chicago IL.
December – 2011	Masters of Science in Nursing Education Northern Illinois University, DeKalb, IL.
May – 1990	Bachelors of Science in Nursing Northern Illinois University, DeKalb, IL.

### Major Area of Concentration in Practice

---

Pediatric Critical Care, Pediatric Oncology/Hematology/Stem Cell Transplant, Pathophysiology, Nursing Education, Qualitative Research, Research Supporting Families During Life-Threatening Childhood Illness

### Professional Experience:

---

2013 to present	The University of Chicago Medicine, Comer Children's Hospital, Chicago, Illinois <ul style="list-style-type: none"><li>○ Clinical Nurse Educator: Pediatric Hematology/Oncology/Stem Cell Transplant Unit, Complex Intermediate Care Unit, Pediatric Intensive Care Unit</li></ul>
1991 to 2013	Ann and Robert H. Lurie Children's Hospital (Children's Memorial Hospital), Chicago, Illinois <ul style="list-style-type: none"><li>○ Pediatric Intensive Care Unit (PICU), Staff Nurse: 1991 to 1995; 1999 to 2006; 2009 to 2013</li><li>○ Pediatric Critical Care Transport Team, Staff Nurse: 2007 to 2009</li><li>○ Pediatric Intensive Care Unit, Clinical Nurse Educator: 1995 to 1999</li></ul>
2012	William Rainey Harper College, Palatine, Illinois Adjunct Clinical Supervisor (January to December 2012)
1990 – 1991	Loyola University Medical Center, Maywood Illinois Neonatal Intensive Care Unit, Staff Nurse

#### Awards, Honors, Scholarships:

---

- Nominated (April 2019): Award for Excellence in a Specialty or Leadership Nursing Role, The University of Chicago Medicine
- The Society of Pediatric Nurses: Research Grant, 2018 (Supporting Families Through the Acute Phase of the Pediatric Hematopoietic Stem Cell Transplant Experience: Perspectives from Parents and Nurses)
  -
- The Daisy Foundation: Research Grant, 2018 (Supporting Families Through the Acute Phase of the Pediatric Hematopoietic Stem Cell Transplant Experience: Perspectives from Parents and Nurses)
  -
- Phi Kappa Phi Honor Society - April 2017
- Golden Key International Honour Society - September 2016
- The Daisy Foundation: Research Grant, 2015 (The Experience of Children Undergoing <sup>131</sup>I-Metaiodobenzylguanidine Therapy and the Parents and Nurses Who Care for Them: A Qualitative Descriptive Study)
  -
- Sigma Theta Tau International, Honor Society of Nursing – December 2011
- Exemplar Nurse Consultant, 2004 – Ann and Robert H. Lurie Children’s Hospital of Chicago
- Prince Scholar, February 1996, Ann and Robert H. Lurie Children’s Hospital of Chicago (Cardiopulmonary Resuscitation (CPR) Instruction for Parents)

#### Book Publications:

---

Pietsch, J., & **Lankin, K.** (2013). Overview of solid organ transplantation (heart transplant). In M.F. Hazinski (Ed.), *Nursing care of the critically ill child*, 3<sup>rd</sup> ed (pp.869-873). St. Louis, Missouri: Elsevier.

**Lankin, K.** (2008). Central venous non-tunneled catheter: Central venous pressure monitoring. In J.T. Verger & R.M. Lebet (Eds.), *AACN procedure manual for pediatric acute and critical care* (pp. 1063-1068). St. Louis, Missouri: Saunders.

**Lankin, K.** (2008). Central venous non-tunneled catheter: Insertion assist. In J.T.Verger & R.M. Lebet (Eds.), *AACN procedure manual for pediatric acute and critical care* (pp. 1048-1054). St. Louis, Missouri: Saunders.

## Poster Presentations

---

**Lankin, K.,** LaFond, C., & Yost, A. (2019). *Nurses' experiences caring for children receiving <sup>131</sup>I-Metaiodobenzylguanidine (MIBG): A qualitative descriptive study*. The University of Chicago Medicine Nursing Research and Evidence-Based Practice Symposium. Chicago, Illinois

**Lankin, K.,** & Bruce, L.A. (2018). *Care and discharge of the newborn transitioned from the neonatal intensive care unit: An education initiative (poster)*. Society of Pediatric Nurses Annual Conference, Denver, Colorado.

Kirk, A., **Lankin, K.,** & LaFond, C. (2017). *The experience of children receiving <sup>131</sup>I-Metaiodobenzylguanidine therapy and their caretakers: A qualitative descriptive study (poster)*. Society of Pediatric Nurses Annual Conference, West Palm Beach, Florida.

**Lankin, K.,** & Hershberger, P. (2016). *Psychological effects of children's stem cell transplantation on parents and siblings: Findings from a systematic literature review (poster)*. The University of Chicago Medicine: 2016 Annual Nursing Research and Evidence-Based Practice Symposium. Chicago, Illinois

**Lankin, K.,** Monroe, T., & Johnson, L. (2016). *Peer review: Fostering growth of the nursing professional development practitioner (poster)*. The University of Chicago Medicine: Quality Symposium. Chicago, Illinois.

Kirk, A., **Lankin, K.,** & LaFond, C. (2015). *The experience of children receiving <sup>131</sup>I-Metaiodobenzylguanidine therapy and their caretakers: A qualitative descriptive study (poster)*. The University of Chicago Medicine: 2015 Annual Nursing Research and Evidence-Based Practice Symposium. Chicago, Illinois

**Lankin, K.,** & Kirk, A. (2015). *Development and Implementation of an MIBG Program for the Treatment of Neuroblastoma Using a Multidisciplinary Approach (poster)*. Society of Pediatric Nurses Annual Conference, Anaheim, California.

## Podium Presentations

---

**Lankin, K.,** LaFond, C., & Yost, A. (2019). *Nurses' Experiences Caring for Children Receiving <sup>131</sup>I-Metaiodobenzylguanidine (MIBG): A Qualitative Descriptive Study*. The Midwest Nursing Research Society Conference, Kansas City.

**Lankin, K.** (2010). *Fast and furious: Management of SVT in the pediatric patient (presenter)*. Lurie Children's Hospital Transport Team Conference, Chicago

**Lankin, K.** (1999). *Basic concepts in hemodynamic monitoring (presenter)*. The Contemporary Forums Annual Pediatric Critical Care Nursing Conference, Chicago.

---

## Ongoing Research

---

JPB-2014-54-A LaFond (PI) 2014 - current  
The Experience of Children Undergoing <sup>131</sup>I-Metaiodobenzylguanidine Therapy and the Parents and Nurses Who Care for Them: A Qualitative Descriptive Study  
The question this qualitative descriptive study seeks to answer is -how do children and their caretakers (parents, nurses) describe their experience(s) with <sup>131</sup>I-MIBG therapy? We are specifically interested in the perceived emotional and physical stressors during treatment and isolation, and the actions or situations that facilitate coping (Funded by the Daisy Foundation).  
Role: Co-Investigator

Dissertation Research (IRB 19-0308) Lankin (PI) 2018 - current  
Supporting Families Through the Acute Phase of the Pediatric Hematopoietic Stem Cell Transplant Experience: Perspectives from Parents and Nurses  
This study purpose is to gain insight on the support systems in place for families, and describe parental stressors, coping, and adaptation during the acute phase of hematopoietic stem cell transplantation when the child is hospitalized from two different viewpoints of the parents and the nurses who care for these children  
Role: Principle Investigator

## Related Professional Experience:

---

The University of Chicago Medicine (UCM)

### *Council and Committee Work:*

- Unit Based Council, Co-Chair: Center for Nursing Professional Practice and Research (CNPPR), June 2013 to June 2014
- Unit Based Council, member: Center for Nursing Professional Practice and Research, June 2013 to present
- Unit Based Council, Member: Pediatric Hematology/Oncology, March 2013 to March 2017
- Unit Based Council, Member: Pediatric Intensive Care, March 2017 to present
- Pediatric CPR Committee, June 2013 to present

### *Evidence Based Practice Projects:*

- Pediatric Sepsis Taskforce: Member, October 2013 to present
- Implementation/Staff Education of the Pediatric Early Warning Score (PEWS) – 2014 to present
- Implementation/Staff Education for <sup>131</sup>I-MIBG therapy – 2014
- Restructure of the Hematology/Oncology Orientation Process – May 2013 to May 2015
- Restructure of the PICU Nursing Orientation Process (orientation checklist, required classes, preceptor responsibilities) – 2017 to present
- Development of a Pediatric Cardiac Surgery Program – 2018 to present

### *Mentoring/Precepting:*

- Graduate Student (MSN in Education): Kristin Becker, January to June, 2014 (Project: Pediatric Early Warning Score – PEWS)
- Graduate Student (MSN in Education): Lee Ann Bruce, August to December, 2016 (Project: Care and discharge of the newborn transitioned from the neonatal intensive care unit: An education initiative)



- Graduate Student (MSN in Education): Lindsay Kamin, January to July, 2018 (Project: Peripheral Intravenous Catheter Infiltrates: Identification and Prevention of IV Infiltration)
- Graduate Student (MSN in Education): Madalyn Mazur, March 2019 to October 2019 (Project: Skin Care Guideline for Pediatric/Neonatal ECMO Patients – Guideline Development and Education)

## Lurie Children's Hospital

### *Council and Committee Work:*

- Standards Committee Member: PICU, August 1995 to March 2013
- Peripheral IV Task Force Member: PICU, June 2011 to March 2013
- Education Committee Member: PICU, August 1992 to December 2006
- IV Drip Taskforce, Chair: PICU, March 2005 to December 2006

## Teaching

### *Selected educational presentations, University of Chicago Medicine*

---

#### Alterations in Cardiovascular Function (presenter)

- Congenital Heart Disease
- Cardiac Disease in Children
- Care of the Child Post Cardiac Catheterization

#### Pediatric Critical Care Neuroscience Review (presenter)

- Increased Intracranial Pressure
- Review of Intracranial Pressure Monitoring Devices

#### Care of the Pediatric Oncology and Hematology Patient (presenter and facilitator)

- Oncologic Emergencies
- Childhood Malignancies: Hematologic
- Childhood Malignancies: Solid Tumors

#### Care of the Pediatric Hematopoietic Stem Cell Transplant (HSCT) Patient (presenter and facilitator)

- Conditioning Regimens for Pediatric HSCT
- Stem Cell Infusion: Monitoring and Complications
- Infection and Sepsis in Pediatric HSCT
- Toxicities in Pediatric HSCT: Cardiac, Pulmonary, Neurological, Liver, Renal, Gastrointestinal

#### Pediatric CCRN Review Course, June 2017 and March 2020 (presenter and facilitator)

- Test Taking Strategies for the CCRN Exam
- Increased Intracranial Pressure in the Pediatric Patient
- Congenital Heart Disease: Defects and Care
- Care of the Pediatric Trauma Patient

*Selected educational presentations, Ann and Robert H. Lurie Children's Hospital*

Pediatric CCRN Review Course, Lurie Children's Hospital: Biennial from August 1999 to August 2007 (presenter and facilitator)

- Increased ICP in the Child with a Brain Injury
- Test Taking Strategies for the CCRN Exam

Lurie Children's Hospital PICU Orientation Class Day: Biannual from August 1992 to December 2006 (presenter and facilitator).

- Care of the Neurologically Injured Child in the PICU
- Review of ICP Monitoring Devices

Licenses and Certifications:

---

1990-present	Registered Nurse – expires 5/31/2022
1987-present	CPR – expires 7/31/2022
1992-present	PALS – expires 3/31/2022
1996-present	Pediatric CCRN-K – expires 10/31/2023
2018-present	ACLS – expires 12/31/2021

Professional Memberships:

---

American Association of Critical Care Nurses (AACN)  
Association of Pediatric Hematology/Oncology Nurses (APHON)  
Society of Pediatric Nurses  
Sigma Theta Tau  
Midwest Nursing Research Society  
Phi Kappa Phi